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**Quality Of Life Experiences Of Parents Of
Children With Autism In Scotland**

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PhD in Social Work

The University of Edinburgh

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Declaration

I declare that this thesis has been composed solely by myself and that it has not been submitted, in whole or in part, in any previous application for a degree. Except where stated otherwise by reference or acknowledgement, the work presented is entirely my own.

Deepa Kuriachan

ABSTRACT

The purpose of this study was to enter the world of the parents living with a child with autism, wondering what quality of life means for them and whether their engagement with social work services makes any difference to their quality of lives. Understanding the quality of life experiences of the parents of children with autism is relevant for policy making and social work practice.

Based in a Scottish context, the objectives for this research were as follows:

To explore the parent carers' description of the term quality of life

To describe the parent carers' views on their quality of life in the context of the services provided by social services within (departments of) local authorities.

To understand the systems, processes and procedures put in place by the local authorities to support parent carers

To explore the scope for changes, if any, in the present social work approach in order to enhance the quality of life of parent carers.

The study adopted a grounded theory methodology informed by a symbolic interactionist theoretical framework. Data were gathered from three study local authorities in Scotland. The participants include an almost equal number of male and female parents (total parent participants = 23); and social workers and operational managers from three study local authorities (total number of social workers =12, total number of operational managers =3). This study utilised focus groups and semi structured interviews to gather data. Using the constant comparison method, three main categories emerged; namely 'new normal', 'on-going burden' and 'limited help' which contextualised the quality of life experiences of parent participants in the study. Oppression emerged as the overarching theory. Drawing on the

parental perspectives on quality of life distilled in this study, the implications for further research, professional practice and education are explored.

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List of Abbreviations

ADHD	Attention deficit hyperactivity disorder
ASC	Autism spectrum condition
ASD	Autism spectrum disorder
CRPD	Convention on the Rights of Persons with Disabilities
DLA	Disability Living Allowance
DSM	<i>Diagnostic and Statistical Manual of Mental Disorders</i>
GDP	Gross Domestic Product
GIRFEC	<i>Getting It Right for Every Child</i>
GP	General practitioner
GTM	Grounded theory methodology
HDI	Human Development Index
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual disability
IPA	Interpretive phenomenological analysis
NHS	National Health Service
PDD	Pervasive developmental disorder
PECS	Picture Exchange Communication System
PHIS	Public Health Institute of Scotland
PIP	Personal Independence Payment

PSI	Parenting Stress Index
PWI	Parent Wellbeing Index
QLI	Economist Intelligence Unit Quality of Life Index
QOL	Quality of life
SDS	Self-directed support
SIGN	Scottish Intercollegiate Guidance Network
SSPS	School of Social and Political Studies
UK	United Kingdom
UNDP	United Nations Development Program
US	United States
WHO	World Health Organization

Chapter 1: Introduction

Through the blur, I wondered if I was alone or if other parents felt the same way I did—that everything involving our children was painful in some way. The emotions, whether they were joy, sorrow, love or pride, were so deep and sharp that in the end they left you raw, exposed and yes, in pain. The human heart was not designed to beat outside the human body and yet, each child represented just that—a parent's heart bared, beating forever outside its chest.

——Ginsberg, 2000, p. 1

British author Debra Ginsberg has chronicled her long-term struggle with her son who had autism *in her lovely book* Raising Blaze: A Mother and Son's Long, Strange Journey into Autism.

During my social work training in India, I had the opportunity to interact and engage with children with autism and their families. I was intrigued by the world of autism, especially the unique and challenging behaviours presented by autism. The resilience and commitment of the parents of these children struck a chord in my head and heart.

The spin of life events brought me to Scotland where I began my career as a support worker for young people with complex disabilities including autism and later progressed to work as a social worker in a local authority catering to a client group with learning disability and autism. This experience of engaging with an autistic client group and their families reignited the passion that I had for them. When my passion was coupled with my interest in research and academia, there began my PhD journey.

The researcher in me began to undertake some diligent reading and quickly realised that autism is an area that could benefit from further research, given that 1 in 100 people (not differentiated into children and adults) in the United Kingdom is estimated to have autism (The National Autistic Society, 2015). As I had been living and also working in Scotland, I was naturally interested to know more about it from a Scottish perspective. To my surprise, there was very limited data on the prevalence of autism in Scotland. The Public Health

Institute of Scotland (PHIS, 2001) continues to be the only available source of data that quantifies autism in the Scottish context. PHIS suggests that 60 in 10,000 children have autism spectrum disorders with a likely increase in numbers in the coming years. This would imply an increase in the number of parents who will be affected by a child's autism.

The review chapter on current and past literature in this field sheds more light on the limited research undertaken with parents of children with autism. The current research study, set in the Scottish context, attempts to capture the quality of life (QOL) experiences of parents of children with autism. Being a social worker, I was a member of the statutory social work team of a local authority responsible for delivering services for children and adults with autism and their families. Hence, I harboured a professional curiosity to understand whether social work services provided by local authorities affected parents' QOL experiences.

I have undertaken extensive field work for this study as evidenced by the recruitment of a substantial number of families from three local authorities and also by the emphasis given to the equal proportion of male and female parent participants. The heterogeneity of the participants is further extended by the participation of parents from other ethnic backgrounds. The chapter on research methodology discusses this in further detail.

Using a grounded theory approach, I developed three main categories—new normal, ongoing burden and limited help—that contextualised the QOL experiences of parent participants in the study. This is elaborated in greater depth in the three findings chapters.

The final two chapters of this thesis include a discussion of the findings and concluding remarks. Table 1 provides an overview of the chapters contained in this thesis.

Table 1: *Overview of the thesis chapters*

Chapter Number	Content
1	Introduction
2	Autism and Autism Spectrum Disorder
3	Legal and Policy Context
4	Literature Review
5	Research Design
6	The Grounded Theory Journey
7	Findings Chapter 1
8	Findings Chapter 2
9	Findings Chapter 3
10	Literature Review Update
11	Discussion
12	Conclusion

Chapter 2: Autism and Autism Spectrum Disorders

2.1 Complexities in understanding and defining Autism Spectrum Disorders

Steve Silberman, in his recently published book *Neurotribes: The Legacy of Autism and the Future of Neurodiversity* (2016), traces the history of autism and its current status. A relatively lengthy discourse nearing 500 pages, it has attempted to provide a convincing description of the complexities of autism, the struggles and successes of individuals and their families, and the emergence of self-advocacy. Why is autism spectrum disorder complex to understand and define? As a PhD student, I have found it nearly impossible to keep up with the changing narratives and increasing influx of research studies across several domains, be it medicine, psychology, disability, policy, social work and so on. The more I read about it, the more confused I become. Despite the fact that autism spectrum disorder has triggered the curiosity of researchers to explain, understand and define this condition, there is a clear lack of consensus on the best model or theory to understand autism spectrum disorder.

While unpacking the history of autism spectrum disorder, Silberman (2016) portrays the conflict between the concept of autism as a disease that needs “prevention” and cure, and autism as a condition of human diversity in which differences and strengths are valued.

2.2 Medical Constructions of Autism Spectrum Disorder (ASD)

Although both Kanner (1943) and Asperger (Frith, 1991) first conceptualized the term autism in the early 1940s, an autism diagnosis did not appear in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) until 1980 in its third edition, when it was classified as a Pervasive Developmental Disorder (PDD; American Psychiatric Association, 1980). Eugen Bleuler coined the term ‘autism’ in the year 1912 (Brill, 2007). He derived it from the Greek word ‘autos’ which means ‘self’ and used it to mean ‘morbid self admiration’.

Prior to this, in the DSM-II, several criteria for childhood schizophrenia including “autistic, atypical and withdrawn behavior” perhaps best characterized autistic symptomology (American Psychiatric Association, 1968). Conceptualizing autism as a continuum of disorders or autism spectrum disorders (ASDs) did not occur in the DSM until 1987. This has been explained further in the sections below. Although researchers are confident that genetics play a significant role in an autism diagnosis, the diagnosis remains behavior based, meaning that clinicians use the DSM to diagnose ASDs on the basis of behavior-based criteria versus biology-based medical testing.

Treatment for ASD ranges from more experimental treatments to pharmacology and behavioural treatments, which have stronger foundation in scientific literature.

2.3 Neuro Diversity and Social Construction of Autism Spectrum Disorder

The neurodiversity movement offers a counter narrative to the ‘autism-as-disorder’ model outlined above. Neurodiversity is defined as a category concerned with promoting the rights of, and preventing discrimination against, people who are neurologically different from the ‘neurotypical’ (or the non-autistic) population (Runswick-Cole, 2014). Proponents of the neurodiversity movement make the claim that autism is not a disorder to be cured, but rather it is a human specificity or difference that involves different ways of socialising, communicating and sensing and that these differences must be respected (Jaarsma and Wellin, 2012). Neurodiversity represents a shift away from psychoanalytic narratives of autistic disorder towards neurobiological and genetic accounts of difference (Ortega, 2009). The neurodiversity movement thus goes beyond simply claiming rights and antidiscriminatory practices for neurodiverse people, but argues for recognition and acceptance of difference. In so doing, autistic self-advocates reject research that focuses on a cure for autism, considering such research

to be oppressive and responsible for diverting much-needed resources from the lives of neuro diverse individuals (Kapp et al., 2012).

Silberman (2016) highlights the positive qualities of autistic individuals who does not have an intellectual disability, have unique abilities, and have relatively effective although unique communication skills. This emphasis on the strengths and unique abilities of individuals with autism, and their interest and ability to advocate for themselves. However, in his zeal to make a stand on 'neuro diversity', he tends to under-represent the individuals with ASD who have intellectual disability, limited communication skills, and challenging behaviour.

It can therefore be inferred that ASD is multi faceted and heterogeneous in nature. The section that follows explains this in further detail.

2.4 What is Autism Spectrum Disorder

Autism is a lifelong developmental disorder more specifically referred to as autism spectrum disorder (ASD) but also known as autism spectrum condition (ASC). ASD affects people differently with some affected individuals being able to live independently. Others will need very specialist support.

What everyone will have in common is difficulty in 3 areas of functioning, sometimes referred to as the triad of impairments. People experience problems with:

- Communication – both verbal and non-verbal, e.g. difficulties with use and interpretation of voice intonation, facial expressions and other communicative gestures;
- Reciprocal social interaction – this includes the ability to understand what someone else might be thinking in a real-time situation and to understand the need for social 'give and take' in conversation and overall interaction;

- Restrictive, repetitive and stereotypical routines of behaviour – these may be very restricting for their family, friends and colleagues but may also be psychologically distressing or inhibiting for the individual with ASD).

2.5 Diagnosis of Autism Spectrum Disorder

There are two major diagnostic classification systems in current use, the International Classification of Diseases, version 10 (ICD-10) by WHO and the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-V) published by American Psychiatric Association (APA). In July 2007, the Scottish Intercollegiate Guidance Network (SIGN) had published a national clinical guideline for the assessment, diagnosis and intervention for children and young people with autism spectrum disorders. The SIGN guidelines encourages the practitioners in Scotland to use either of the two aforementioned classification system for autism diagnosis.

2.6 The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V)

The *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-V) is the update to the American Psychiatric Association's (APA) classification and diagnostic tool released in 2013. DSM-V (2013) is likely to have a significant influence on the next edition of the International Classification of Disorders (ICD-11) expected in 2018. ICD -10 is the most commonly used diagnostic manual in the United Kingdom. It is expected that ICD-11 will closely align with the updates made in DSM-V.

DSM-V defines autism spectrum disorder as “persistent difficulties with social communication and social interaction” and “restricted and repetitive patterns of behaviours, activities or interests” (this includes sensory behaviour), present since early childhood, to the extent that these “limit and impair everyday functioning”.

In DSM-V, the terms 'autistic disorder', 'Asperger disorder', 'childhood disintegrative disorder' and 'Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)' have been replaced by the collective term 'autism spectrum disorder'. This means that it's likely that 'autism spectrum disorder' (ASD) will become the most commonly given diagnosis.

DSM-V has introduced specifiers to help the clinician to describe associated or additional conditions, eg intellectual impairment, language impairment, genetic conditions, behavioural disorder, catatonia.

One of the specifiers relates to the 'severity' of social communication impairments and restricted, repetitive patterns of behaviour. There are 3 levels: requiring support, requiring substantial support, requiring very substantial support. This can allow the clinician to give an indication of how much someone's condition affects them and how much support an individual needs.

The DSM-V now includes a condition called 'social communication disorder', separate to 'autism spectrum disorder'. This would be given where someone exhibits social interaction and social communication difficulties and does not show restricted, repetitive patterns of behaviour, interests or activities.

However, people who receive a diagnosis of autism (ASD) are not automatically eligible for support. DSM-V explains that 'severity' levels may vary by context and also fluctuate over time, that the descriptive severity categories should not be used to determine eligibility for and provision of services, and that these can only be developed at an individual level and through discussion of personal priorities.

2.7 Critical Reflection of DSM-V

National Autistic Society (2016) summarises that the diagnostic criteria in DSM-V are clearer and simpler than in the previous version of the DSM, and sensory behaviours are now included. This is useful as many autistic people

have sensory issues(hypersensitivity or hyposensitivity to sights, sounds, smells, tastes, touch, balance and body awareness which affect them on a day-to-day basis. It now includes 'specifiers' to indicate support needs and other factors that impact on the diagnosis.

There are concerns around the removal from DMS-V of Asperger syndrome as a distinct category. For many people, the term Asperger syndrome is part of their day-to-day vocabulary and identity. It is expected that everyone who currently has a diagnosis on the autism spectrum, including those with Asperger syndrome, will retain their diagnosis. No one will 'lose' their diagnosis because of the changes in DSM-V (National Autistic Society, 2016). There is also a worry that the addition of people with Aspergers to the name "autism" will confuse the public into thinking autism is less severe than it often is; and that it will result in a lessening of the much-needed supports that people with ASD are already fighting hard to establish. (<https://autismandoughtisms.wordpress.com>, 2011).

It is also important to note that DSM-V the strict age requirement, required by previous diagnostic tools (see next section for details) is dropped, i.e. for the triad of impairments to be present in a child or adult before three years of age. Instead stating that symptoms must have been present in early childhood.

Backer (2015) argue that developmental regression may be an early and reliable marker in a number of children with autism. Whilst there appears to be little uniformity in the way developmental regression is defined across research studies, all definitions support that regression involves the loss of a previously attained skill. Two classes of the term regression are identified in autism literature at present namely, language regression and social regression. The average age of the reporting of regression is twenty (20) months and about one third of young children with ASD experience regression (language or social) during preschool period

Volkmar and Reichow (2013) argue that there appears to be some significant potential for diagnostic change. Despite what might conceptually appear to be a broader tent of the autism spectrum, the DSM-V approach seems likely to result in a narrower concept. This raises some concern about the impact on services for children in need as well as for comparison with previous research. It seems likely that some proportion of the people will lose their label and thus potentially lose their eligibility for services. This is further reflected in the discussions chapter.

2.8 Definitions of Autism in ICD-10 and DSM IV

DSM V was published in 2013. I completed the data collection for this research during 2011 to 2012 prior to the release of DSM-V in 2013. Hence, this research is positioned within the framework of the diagnostic criteria elaborated in ICD-10 and DSM-4 which has been summarised in the paragraphs that follows. Based on ICD-10 and DSM-IV, parents of children with a diagnosis of autism was selected for the study because autism was considered the most severe disability in the autistic spectrum and it was also identified as one of the two most common disorders in the spectrum (National Institute of Mental Health, 2008).

ICD-10 is the most commonly used ASD classification system in the UK, although many research studies use DSM-IV or other criteria. The diagnostic criteria for ASD continue to develop as more research is done and our understanding of this condition improves, and they are likely to change with future revisions.

In addition to autism being a pervasive developmental disorder (PDD), autism is also a 'spectrum disorder'. This would imply that different individuals can have varying presentations for the same diagnosis. Autism can exist side-by-side with a combination of other symptoms like gastro intestinal issues, seizures, mental illness or other conditions like learning disability and attention deficit hyperactivity disorder. There are several diagnostic headings within the spectrum of autistic disorders which primarily

appear as subgroups of pervasive developmental disorders in DSM-IV (1994) and ICD-10 (1990). The subgroups are as follows:

Autism: in autism the impairments in the social and communication areas are quite pronounced, severe and sustained and present before the age of three years. The child is often anxious, has poor attention span and lacks motivation, responds unusually to many different stimuli and is very 'different' from other children. The child may also be intellectually delayed.

Asperger Syndrome (also known as High Functioning Autism): in Asperger syndrome there are severe and sustained impairments in social interactions, but impairments are not as severe in the communication area. The impairments seem more subtle in the very young child, and become more apparent as the child reaches preschool and school age. The Asperger child/adult is usually in the normal or high intelligence range and hence it is sometimes referred to as a 'Little Professor' syndrome.

Childhood Disintegrative Disorder: the children in this group have a period of entirely normal development before the onset of the disorder, but is followed by a definite loss of previously acquired skills in several development areas over the course of a few months. Language, social skills as well as motor skills can degenerate over time.

Rett's Syndrome: This condition, so far has been found only in girls, in which apparently normal early development is followed by partial or complete loss of speech and of skills in locomotion and use of hands, together with deceleration in head growth. The usual age of onset is between seven and twenty-four months of age. Hand-wringing stereotypes, hyperventilation and loss of purposeful hand movements are characteristic.

PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified):

This is a term used to include children/adult who cannot be classified in any of the above detailed headings.

The final essential factor considered before making a diagnosis of autism is the child's age. According to the International Statistical Classification of Diseases and Related Health Problems (ICD-10) published by World Health Organisation (WHO, 1990) and the Diagnostics and Statistics Manual of Mental disorders (DSM IV) of the American Psychiatric Association(1994), all the above mentioned symptoms should have been present in the child before 36 months. It is worth noting that the age factor (that is for the child to present with issues mentioned above before three years) has been eliminated in the revisions made in DSM - V.

2.9 Impact of DSM - V on this Research Study

It is the recommendation of the work group that worked on the development and implementation of DSM-V that those who received their diagnosis based on DSM-IV will retain their diagnosis (Kulange et al., 2014). It is also noted that in the United Kingdom, autism diagnosis is provided based on the ICD - 10 which is pending official updates in 2018. It is predicted that ICD -11 will be closely aligned with the DSM-V with respect to assessment and diagnosis of autism. It remains uncertain how the revisions in ICD-11 will impact the children of the parents who participated in the study. One major concern could possibly be around retaining their diagnosis and their entitlement for current service provision.

The next section details the theories that contributed to the understanding of autism.

2.10 Explanatory Theories of Autism

There are several theories that have been put forward to explain the causes of autism have formed the basis of the popular understanding of autism in the public and scientific community. Although some of these theories have changed or have been abandoned by the scientific community, they contribute to the lingering ideas in the popular understandings of autism and may be responsible for some of the misconceptions that continues,

2.10.1 Refrigerator Mothers Theory

In the early years of awareness of autism in the mid- twentieth century, autism was believed to be a solely psychological condition with no organic – that is, physical or neurological—basis at all. Child psychologist Bruno Bettelheim, in his 1967 book, *The Empty Fortress*, argued that autism was caused when a child withdrew from the unbearable rejection of a cold, unresponsive mother. This mother, it was suggested, had not wanted the child prior to the delivery and still the same even after delivery, whether consciously or unconsciously.

This view of autism was obviously very destructive and factually incorrect. Not only did it have no basis in fact, but it placed a terrible burden of blame on the mother who was already devastated by her child's condition. To make things worse, when anyone studied families with an autistic child, they found the mothers were depressed, stressed out, overwhelmed and not very available, all of which was interpreted as support for the “refrigerator mother” theory rather than the impact of this condition on the mother.

It appears that this theory and its proponents had a narrow view on the interaction of mothers with the children with autism attributing the cause of autism to the mother's inadequate communication and synergy with her child. However, it conveniently ignored the fact that in most cases there is a lack of reciprocity from child's side towards the mothers' cues.

Several eminent scientists like Rimland (1964) who is the author of '*Infantile Autism: The syndrome and its implications for a Neural Theory of Behaviour*' argued against the lack of parental affection as the cause of autism. He highlighted a major flaw in this theory by establishing that parents who fitted the 'refrigerator' stereotype also had children who did not have autism.

2.10.2 Genetic Causations of Autism

Scientists have always been keen to explore the influence of nature (genetics) on autism and to understand this, they studied twins. What scientists were interested in was "concordance" that is, the percentage chance that if one twin has autism, the other twin will also have autism. If the identical twins had a higher concordance than fraternal twins, then it would imply that the difference is due to the increased amount of genetic material shared by the identical twins, and that autism is influenced by genetics. Folstein and Rutter (1977) conducted the first study on eleven identical twins and 10 fraternal twins in Great Britain. The study found that the concordance for identical twins was 36% while that of fraternal twins was 0%. Although this study was small in size, it provided the first evidence that autism may have a genetic origin. A dozen further twin studies have confirmed the observation of this pioneering study (Ronald & Hoeksma, 2014).

Sanders et al. (2011) suggest that a small proportion of autism cases are likely to be caused by *de novo* (new) mutations. In most of the cases, a baby's genetic material is a byproduct of the genes present in the egg and the sperm derived from their mother and father. However, in rare cases the egg and the sperm can contain genetic material that is not present in either of the parents. This phenomenon *de novo* mutations. It is argued that some people with autism may have inherited *de novo* mutations which may have an effect on brain development.

Once scientists had established that the cause of a disorder was influenced by genes, the next task was to identify the exact genes that might be involved. However, after several decades of intensive research, scientists

could find no one genetic mutation that all individuals diagnosed with autism shared. It was this lack of findings that led scientists to stop thinking of autism as one condition with one cause. (Whitehouse & Stanley, 2013).

For a considerable time scientists were searching for one clear brain difference that may lead to autistic behaviours. However, this hope has yet to be fulfilled, with few studies identifying brain characteristics that are shared by different individuals diagnosed with autism. This may be a further indication that autism has many different causes (Whitehouse et al., 2013). One prominent theory that emerged from the brain imaging studies explain under connectivity with long range connections but over connectivity with short range connections. If this is found to be accurate, these brain differences may be able to explain why some individuals with autism have difficulties with complex tasks that require the integration of information from multiple brain regions (such as cognitive and social abilities), but have no difficulties, or even enhanced abilities, for tasks that require less integration across brain areas (such as sensory processing).

Researchers have also attempted to put forward genetic explanations for a higher percentage of males diagnosed with autism in comparison to females. Skuse and Marco (2000) suggest that the gene or genes carrying autism are located in the X chromosome. Girls inherit X chromosomes from both parents, but boys only inherit one, -from their mothers. Their hypothesis is that the X chromosome which girls inherit from their fathers contains an imprinted gene which 'protects' the carrier from autism, making girls less likely to develop the condition than boys.

Lord and Schopler (1987) have outlined several possible mechanisms for the transmission of autism on the sex-linked X chromosome, and also for autosomal transmission (involving non-sex chromosomes).

It can be concluded that the models discussed above are theoretical and researchers are yet to find a single genetic cause for autism. There is a general acceptance that autism is caused by changes in the brain structure

and development. Whilst there are studies implying that there are many families that present with a pattern of autism and related disabilities highlighting the potential for a genetic cause, researchers continue their investigations into the links of autism and heredity, genetics and medical conditions (National Autistic Society, 2016). In addition to the genetic causation explored by researchers, there also exist a number of sociological and psychological theories to explain the cause of autism. The major two are discussed in the next sections.

2.10.3 Theory of Mind and Autism

In his 1995 book, "Mind blindness: An Essay on Autism and Theory of Mind," Simon Baron-Cohen explored what has become one of the central theoretical concepts of autism: *theory of mind*.

Baron-Cohen proposal is based on the premise that children with autism suffer from *mind blindness*. These children with autism are already hampered by the inability to achieve joint attention with others. Due to this they become unable to build on that fundamental step to intuit what others are thinking, perceiving, intending, or believing. They become "blind" to others' mental states and expressions.

A non autistic human being can "mind read" easily and naturally. They are not psychic in the real sense; but they are simply wired from birth to quickly amass the capacity to make a good guess at what others are thinking or planning. This is essential for all the beings who are not only social creatures, but who have the potential to be each other's predators. The ability to identify whether another human is friend or foe is vital and necessary to his/her survival. Is the person approaching with that base ball bat going to ask me to play base ball or smash my skull in with it? For man's survival instant judgments must be made, and action be taken at short time spans. To lack this ability means to be blind to others' intentions or beliefs, and this puts the person with autism at a terrible disadvantage.

2.10.4 The Extreme Male Brain Theory

In 2002, Simon Baron-Cohen expanded on his *mind blindness* theory by weaving in another concept: empathy. He classified the brains of humans to two “types”: an *empathizing*, female brain (which, on average, more women would have) and a *systemizing*, male brain (which, on average, more men would have).

“Empathizing, he wrote, is the drive to identify another person’s emotions and thoughts, and to respond to these with an appropriate emotion. Empathizing allows you to predict a person’s behaviour, and to care about how others feel. Systemizing, on the other hand, is the drive to analyze the variables in a system, to derive the underlying rules that govern the behaviour of a system. Systemizing allows you to predict the behaviour of a system –rather than human beings-- and to control it.”

A very balanced human would possess both these abilities in equal measure, with the average man's brain predisposing more towards the side of systemizing, and the average woman leaning more heavily onto the side of empathizing. In contrast, people with autism spectrum disorders overwhelmingly lack the ability to empathize, to read via expression, body language, actions, and words emotions, intentions, and perceptions. This notion builds on the mind blindness concept by including a more specific emotional aspect. A person with an ASD has trouble reading not just thoughts, but feelings.

It's evident that the proponents of this theory believe that although people with ASDs lack a strong empathetic sense, they are viewed as incredible systemisers. They seem to possess an 'extreme male brain'. Because of this type of brain, their deficits will be in the realm of deciphering other humans' mental states and feelings, and predicting or manipulating their behaviour. They might excel on the other hand, at evaluating non-human systems, such as machines, scientific phenomena, or a collection of objects, down to the lowest level of detail. The extent to which they are “hyper-

systemisers” will vary with their level of functioning. The more autistic a person is, the less capacity they will have to adapt to or interact with systems that are not 100% predictable. A very low functioning autistic person may line up objects in the same order again and again; while a higher functioning individual might be able to program computers.

Understanding behaviours and emotions of other people that we daily encounter depends upon a rapid, swift ability to adapt to barely predictable, infinitely variable human actions. Because the person with ASD are hyper-systemisers, who can easily cope with logical, lawful systems but not with systems of “high variance or change (such as the social world of other minds),” people with ASDs become resistant to change, clinging to routine and appears to have a monotonous life.

2.10.5 Remarks

Whilst the introduction of alternative theoretical models linked to genetics and mind blindness certainly took the edge off the negativity towards the mothers in the popularised 'refrigerator mothers' theory in the 1960s, Cohen's theory of mind appears to paint those with autism as having deficits in their skills to understand others. Although it may be acknowledged that those with autism do appear to present with social skill difficulties, the limited advances in the medical causes of autism and the lack of research focusing on those on the autistic spectrum certainly highlight the void for an alternative narrative. Given the understanding that those with the diagnosis of autism (arguably the most severe in the ASD) have limited communication abilities, it is highly probable that they may struggle to articulate a defence proposition to the 'absence of empathy' in them argued in the mind blindness theories. Having said that, accounts of the parents of the children with autism could perhaps be the closest a researcher may get to understand their child's world of autism.

2.11 Prevalence of Autism

There is no register or exact count kept in connection with the number of people affected by ASD in Scotland. So any information about the approximate number of people with autism in the community must be derived from the epidemiological surveys (from studies of distinct and identifiable populations). The latest available prevalence studies of autism indicate that 1.1% of the population in the UK may have autism. This roughly equates to over 695,000 people in the UK who may have autism. This calculation is derived from the 1.1% prevalence rate applied to the 2011 UK census figures.

The prevalence study of children, quoted here was done by Baird G. *et al.* (2006) who looked at a population in the South Thames area. This study looked at the prevalence rates among nine to ten year olds in the south of England and they noticed that the total prevalence of ASD in 9-10 year olds was 116.1 per 10,000.

There is only one known prevalence study to have been done of an adult population in the United Kingdom. This was done by Brugha *et al.* in two parts. The initial one in 2007 was done as a report for NHS Information Centre. Their team found a ASD prevalence of 1% among adults living in public households in England. Later in 2011 the same team corrected the overall prevalence among adults in England to 1.1%, after incorporating data from a new study that looked into the prevalence of autism among adults with learning disabilities living in private households and communal care establishments in Leicestershire, Lambeth and Sheffield.

Another survey in this field is the one done by Green *et al.* in 2004 for the Office of National Statistics looking at the mental health of children and young people in Great Britain and they found that one per cent of children aged 5-16 had autistic spectrum disorder. The significant majority of this (82 per cent), were boys.

The Public Health Institute of Scotland (PHIS) reviewed ASD prevalence studies and estimated that there were 7,714 children under 19 in Scotland with ASD, in 2011. But this figure was based on a previously published ASD prevalence rate of 70.3 per 10,000 in pre-school children.

The Scottish Society for Autism has estimated that 1 in 110 of the Scottish population has autism. This roughly translates to 45,000 people in Scotland having the condition. Although there is very limited data to indicate any significant increase in the prevalence of ASD, it is widely believed that the incidence of ASD in Scotland is on the rise. For example in a local review of services for children with disabilities in the City of Edinburgh, Black *et al.* in 2000 noted an increase in the identification of children with autistic spectrum disorder.

This increase in incidence may be interpreted as an actual increase in the number of children affected by ASD, or it can be argued that improvements in the diagnosis and treatment of ASD have lead to more individuals being diagnosed with the condition (PHIS, 2001).

2.12 Concluding Remarks

Autism spectrum disorder is complex to understand and define, yet the data on prevalence suggests that supporting people with autism is a key challenge to policy makers in the United Kingdom, of more interest, in Scotland. The incidence of autism appear to be on the rise. This would mean that children and adults with autism will equate to a substantial proportion of the population in Scotland in the future. While tensions between 'autism as a disease' (medical model) versus 'autism as a difference' (neuro diversity) is playing out in the discourse relating to autism, it is argued that there is an under representation of the perspectives of those with autism who are on the severe end of the spectrum. This can be attributed primarily to the restrictions

in their communication abilities. However, any strategies, policies and interventions developed to enable those with autism lead a happy, fulfilling life will have to be founded on the understanding autism from the perspectives of children and adults with autism and their families. Given the limited capacity to communicate, the closest a researcher could get to a child's world of autism is by exploring the perspectives of their parents. Hence, there is scope for a research study to explore the same in a Scottish context.

Chapter 3: Legal and Policy Context

This chapter will look at the important legal and policy developments from the Scottish Government (which is the executive branch of the devolved government in Scotland) responsible for setting and implementing policy objectives for Scotland. I have attempted to initially outline the legal and policy framework from a factual perspective and this is followed by a critical discussion of the same in the autism context which is captured under the headings of remarks and implications.

It is my understanding that the legal and policy context in Scotland is in a state of flux at the current time, with changes in the political and economic landscape influenced by Brexit, projected welfare reforms, personalisation, integration of health and social care and so on. At the time of completing my field work in 2011-2012, the policy and legal context relevant to autism in Scotland was taking shape in the form of Scottish Strategy for Autism, Self Directed Support and welfare reforms. However, the findings of this study does indicate that these emerging trends had not transpired to bring about any drastic changes in the service provision or help (which was rather limited and scattered at the time) for children with autism and their families.

The section that follows provides a factual synopsis of the legalisations and policies in Scotland that is relevant in the context of this study.

3.1 Legislations and Policies : Scottish Context

At the time of writing this section (2007 -2010), there is no specific legislation in Scotland relating to Autism Spectrum Disorder. However, the Autism (Scotland) Bill was introduced to the parliament as a private member's bill in 2010 pushing for a Scottish version of the Autism Act which received royal assent in 2009 in England. While the Bill argued that legislation is the only

way meet the needs of those with ASD in Scotland, the Parliament did not appear to be convinced for a need of a specific legislation for Autism. Instead, they decided to follow the footsteps of Northern Ireland (who opted for a strategic approach rather than a legislative approach) by committing to the development of a Scottish Strategy for Autism that came into effect in November 2011.

Having said that, there are a number of existing legislations in Scotland, such as the Children (Scotland) Act 1995, Social Work (Scotland) Act 1968 and so on that expect local authorities to cater to the needs (if any) of children and their families for a better quality of life. These legislations are further unpacked in the subsequent policy documents that was published (details below). In the absence of specific legislations, for example, no legislation for carers (this has now changed with the introduction of Carers Recognition (Scotland) Act 2016). Rather than having a specific legislation defining how support should be provided to people with autism, Parliament has defined policies by a variety of strategy papers. For instance, Carers Strategy document. Despite a raft of policy initiatives and current legislations, it is argued that ASD is frequently overlooked.

3.1.1 Scottish Strategy for Autism

In Scotland, the needs of children and adults who was identified as requiring support and assistance from health, social care or education are catered predominantly through the learning disability pathway or mental health pathway for adults, and children with additional needs pathway for children. There was a growing recognition that children and adults with ASD did not necessarily fall within the categories of learning disability and mental health and is more likely to fall through gaps of the existing service provisions. On the other hand, there was also an acknowledgement that ASD has a significant impact on the whole life experience of people and their families. These families need to be supported by a wide range of services such as education, housing, employment, social care, and other community based

services. This led to the development of Scottish Strategy for Autism which became applicable as of November 2011. This strategy identifies ASD as a national priority and outlines a 10 year goal plan to work towards better diagnosis, post diagnostic support, improved coordination between health, social care and other services, better collaborative working between agencies at the national and local level and recommending best practice guidelines. This strategy was a work in progress at the time of data collection of this research, hence it is not surprising that the findings of this research study does not pick up any major impact of this strategy on the quality of lives of children with autism and their families.

3.1.2 Caring Together: The Carers Strategy for Scotland 2010-2015

Yet another strategy that is important in the autism context of Scotland is the Caring Together (Scottish Government, 2010) which recognises the enormous contribution unpaid carers make to the health and social care system and commits to working with carers as equal partners in the planning and delivery of care and support. It is acknowledged both locally and nationally that Health and Social Care services depend heavily on the care provided by partners, family members and others, especially with the increasing challenges posed by an ageing population.

The economic contribution that unpaid carers make to the economy is enormous. It is estimated that the carers save statutory services an amount of £7.6 billion per year in Scotland. This significant social and economic value of unpaid carers is indispensable to society's ability to cope with the ever-increasing demand for services.

It is the assumption of this research study that the unpaid carers mentioned in this document would also allude to the parents of children with autism as they live with the child and undertake the care giving responsibilities. Again, the findings does not reflect the parents (carers) of children with autism feeling recognised, valued or supported. We now understand that there has been a legislative development in this area with the introduction of Carers

Recognition (Scotland) Act 2016. It will be interesting to see if the regulatory powers of this legislation would push for more assertive support mechanisms and provisions for parents of children with ASD in the future.

3.1.3 The Children (Scotland) Act 1995 and GIRFEC

Among other things this requires local authorities to protect and promote children's welfare and to prepare children's services plans. It gave local authorities in Scotland additional duties and powers to respond to the requirements of children "in need" which includes children with disabilities. In the context of this study, this act asserts that a child with autism is more likely to fit the description of child in need and hence would be eligible for consideration of the multitude of services offered by the local authorities.

The Children (Scotland) Act 1995 places a duty on Local Authorities to promote the welfare of children in need (s.22). The definition of children in need (s.93 4(a)) includes

- (i) he is unlikely to achieve or maintain, or have the opportunity of achieving or maintaining a reasonable standard of health or development unless these are provided for him, by a local authority
- (ii) his health or development is likely to be impaired significantly, or further impaired, unless such services are so provided
- (iii) he is disabled
- (iv) he is affected adversely by the disability of any other person in his family

This act puts the onus on local authorities to provide services to the child that will help minimise the effect of disability and lead as normal a life as possible (s23). It explicitly states that every local authority has a duty to undertake an 'assessment' of the child in order to ascertain his/her needs. In conjunction with the needs assessment of the child, the Act requires the local authority to assess the carer's ability to care for the child when asked to do so (s24).

GIRFEC (Getting It Right for Every Child)

GIRFEC outlines the vision of Scottish lawmakers for all Scottish children is clearly outlined in the key policy document *Getting it Right for Every Child* (GIRFEC) (Scottish Government, 2007). This vision is very much consistent with the *UN Convention on the Rights of the Child* and is based on the following eight sets of outcomes (popularly known as SHANARRI indicators) for all policies and services concerned with children and families. The intended outcomes are:

- safe
- healthy
- achieving
- nurtured
- active
- respected
- responsible
- included

Getting it Right for Every Child(GIRFEC) is the main tool for identification and assessment of all the major concerns related to a child's wellbeing. It is helpful to understand GIRFEC is the fundamental framework within which the 'needs' of children with autism is identified and catered to in Scotland, hence provide a benchmark to compare the findings of this study (further details in the discussion chapter 10).

Local authorities are expected to provide the following services for children with disabilities and their families under The Children (Scotland) Act 1995.

(i) Assessment

Assessment of the needs of both the child and the carer is carried out by the local authority (s23), and this is usually coordinated by the social work departments. Following the assessment, a care plan should be developed

for the child (also taking into consideration the outcome of carer's assessment if applicable). It is noted that social work services do not necessarily have to provide direct assistance to the carers, though carers may benefit from the range of services provided for the child he/she care for. This may be subject to change with the introduction of self directed support legislation in 2013, however the data for this research was collected pre 2013.

(ii) General Services for disabled children and families

Community based resources should include information and advice on disabilities, local services, entitlement to welfare benefits, counselling, general support with parenting, occupational, social, cultural and recreational activities.

(iii) Hospital Social Work

Hospital social workers are also an important part of this support network in that they can provide information, advice and support at the time of diagnosis and can provide emotional and practical help such as arranging child care for siblings, or assisting families to obtain travel expenses for hospital visits.

(iv) Services at Home

Social Work departments can arrange a multitude of services at home(if needed) for domestic help, personal care, peripatetic support from education or health services, mobility training, the provision of aids and adaptations in the home, local transport and suitable housing. These are all potentially integral resources that may reduce the impact of disability on a family and also prevent the need for a child to be cared for away from home.

(v) Respite Services

Social work can arrange daytime care, respite services within the child's home, occasional overnight stays and regular periods of care with an

approved family or foster carer, or in a residential home and shared care arrangements with foster or other family carers.

(vi) Residential Care

In special circumstances, the assessment undertaken by Social work department can lead to the recommendation of the child being placed in a specialist residential placement for the development of the child.

(vii) Transition from child to adult services

A child who has a record of needs and has been cared by the local authority must undergo a further needs assessment before his/her 18th birthday in order to make long term plans for his/her future.

3.1.4 The Children and Young People (Scotland) Act 2014

This legislation, again sets context for the health and welfare needs of child with autism to be a specific priority. This act calls on the community planning partners (which may include the local authorities, health boards, third sector and so on) to demonstrate the extent to which children and young people's welfare and health is maximised and their rights are bolstered and protected through joint planning and service delivery across a number of areas. These include:

Increasing the amount and flexibility of free early learning and childcare for 3 and 4 year olds and eligible 2 year olds

Improving permanence planning for looked after children, and supporting the parenting role of kinship carers

enshrining elements of the Getting it right for every child (GIRFEC) approach in law, ensuring a single planning approach for children who need additional support from services, a single point of contact for every child and a holistic understanding of wellbeing

Increasing accountability for progressing actions in children's services plans

3.1.5 Community Care (Direct Payments) Act 1996

This act amended the Social Work (Scotland) Act to allow local authorities to make cash payments to parents to purchase services. This will allow greater independence and control to parent carers on how services are received and delivered for their child. During the period of this research, the power to make direct payments was under this legislation. However this legislation has now been replaced and incorporated in to the Social Care (Self- Directed Support) (Scotland) Act 2013.

Given that the data collection of this study predates 2013, the data does not reflect the implications of this act on the participants of this study.

It would be interesting to explore whether parents of this study are familiar with the self directed support options and ascertain if it is making a difference to their quality of life experiences.

3.1.6 Social Care (Self- Directed Support) (Scotland) Act 2013 and National Strategy for Self Directed Support

The Scottish Parliament recently passed the Social Care (Self-Directed Support) (Scotland) Act 2013. The Act gives people a range of options for how their social care is delivered. They can choose to take a lot of control over their support – for example, through a direct payment or individual service fund – or can choose to take less responsibility and ask the local authority to arrange support on their behalf. The Act requires local authorities to offer people four choices on how they can get their

social care. The choices are:

Option 1 - direct payment

Option 2 - the person directs the available support

Option 3 - the local authority arranges the support

Option 4 - a mix of the above.

The Act contains some other duties and powers, for example a power to local authorities to support unpaid carers and duties on local authorities to give information to help service users make an informed choice.

A ten year National Strategy for Self-Directed Support was produced in 2010 by the Scottish Government and Convention of Scottish Local Authorities (COSLA). The strategy recommends a cultural shift around the delivery of care and support in Scotland, with Self-Directed Support becoming the mainstream dominant approach. The main target of the strategy is on delivering better outcomes through focused assessment and review, improved information and advice, and a clear and transparent approach to support planning. It states that,

“If we are serious about enabling people to exercise choice and control over their lives, then they should be able to maximise choice and control over any formal support they require too.” (Scottish Government 2010, p1)

3.1.7 Education (Additional Support for Learning) (Scotland) Act 2004

This legislation provides context to explore if the data of this research study indicate any assistance or lack of assistance provided to the child with autism from an educational perspective.

This act imposes binding duties on educational authorities/institutions to provide additional support for children and young people. They have a general duty to take into consideration the additional needs of children and young people while carrying out their educational functions. According to this act, ‘additional support need’ means any educational provision provided that is over and above the provision normally provided to children in local mainstream school. Additional needs can arise from a variety of circumstances

such as learning environment (e.g. inflexible curriculum arrangements), family circumstances (e.g. homelessness), disability (e.g. autistic spectrum disorder) and social and emotional factors (e.g. children being bullied).

The only statutory element that is binding to educational authorities is the initiation and implementation of the co-ordinated support plan which contains the record of child's need and the additional support required to meet these needs.

3.1.8 Equality Act 2010

It is estimated that only thirteen percent of the adults with ASD is in full time employment, but with the right support many more could work (National Autistic Society, 2010). This legislation upholds the rights of people with ASD to have equal opportunities to seek employment and request reasonable considerations at work in the context of their ASD. While this research study is not focusing on adults with ASD, it highlights a key issue that a child with autism may face during their transition to adulthood. What is more important is that all public authorities are bound by the Equality Act and so social work services must abide by its requirements.

The Equality Act became law in October, 2010. It replaced previous legislation (such as the Race Relations Act 1976 and the Disability Discrimination Act 1995) and ensures consistency in what employers and employees need to do to make their workplaces a fair environment and comply with the law. An employer must consider making 'reasonable adjustments' for a disabled employee or job applicant if:

- it becomes aware of their disability and/or
- they ask for adjustments to be made and/or
- a disabled employee is having difficulty with any part of their job and/or
- either an employee's sickness record, or delay in returning to work, is linked to their disability.

Men and women in full-time or part-time employment have a right to **equal pay (Sex Equality)** - which in law means 'no less favourable' pay, benefits and terms and conditions in their employment contracts where they are doing equal work.

Employers and employees in the public sector, and in private or voluntary organisations carrying out work on behalf of a public sector employer, have a legal **public sector equality duty** in the workplace to prevent and eliminate discrimination, establish and promote equality and equal opportunities, and foster good relations between people with different protected characteristics.

If an employer believes it is necessary to ask **health-related questions** before making a job offer, it can do so only to determine whether an applicant can carry out a function essential to the role, and/or take 'positive action' to assist disabled people, and/or monitor, without revealing the candidate's identity

3.2 Remarks

The policy developments and legislations clearly outline the vision and commitment of the Scottish Government for the children (with or without disability) and their families (also referred to as carers or unpaid carers in several of the above discussed policies and legislations). Whilst the GIRFEC provides an overarching model for all children services (including education, social work, voluntary sector and so on) to work in a coordinated and collaborative manner to ensure their safety and wellbeing, the Scottish Strategy for Autism, highlighted that children and adults with autism and their families is a national priority. For this study, it can be implied that the Scottish Government have a clear vision for the safety and well being of children with autism and also places expectations on the relevant public bodies (like National Health Boards and Local Authorities) on how this can be achieved.

The legislation pertaining to children specifically spelt out the statutory obligations of the local authorities (section 23 assessment) to assess the needs of children with autism and their families and also listed a number of

potential services that can be streamlined to the children and their families (including respite, welfare payment, aids and adaptations and so on). Self Directed Support is a refreshing concept promoted by the Scottish Government which further clarifies their intention to facilitate greater participation of the parents/families (of the child with autism in this study context) and take control of the care planning of their child. It places the obligation on the assessing body (for a child with autism living in the community - it will be the social work department of the respective local authorities) to ensure that Self Directed Support is used as a framework to allow the child's family to have choice and control over their child's care plan.

However it is important to be mindful at this juncture that the field work for this research study predates the launch of Self Directed Support Legislation in 2013. However, the policies and legislations reinforce the Scottish Government's mission to ensure better quality of life for the parents of children with autism by ensuring better outcomes for children with autism.

3.3 Implications of Policies and Legislations on Service Provision: Autism Context

Autistic children's views and voices: Across the policy areas reviewed, is a common theme of children and young people having a low profile and/or being inadequately involved in decisions affecting their lives. There is need for better consultation and collaboration with disabled pupils about their individual learning plans. It appears common for young people (and their parents) not to be properly involved in transitional planning, and there is a risk that children's views or feelings may be over-ruled within Self directed support and short breaks. Related to this is the paucity of independent advocacy for disabled children across Scotland.

Friendship and social activities: Friends and fun are recurring themes for children with disability. However, difficulties making and keeping friends and accessing social and sports activities are frequent reported (refer to the findings chapters). Lack of support with communication is a major barrier for

some, hindering their participation in social and sporting activities and making friends, and not helped by a shortage of speech and language therapy. A paucity of accessible transport and, for some young people, not being able or allowed to travel independently increases their social isolation. Delays in getting aids and equipment, including wheelchairs, restrict some children's activities. Parents are often disabled children's best advocates and fight hard for them to have valued and fulfilling lives. However, young people need more support to socialise with people near their own age. While some require intensive support or close supervision, others may be subject to an unnecessary level of adult surveillance. the barriers facing disabled children around friendship and social activities are many and complex. More work needs to be done with mainstream recreation and social providers to build their capacity to welcome and include autistic children, highlighting the need for support with friendship, communication and accessible transport.

Self-directed support (SDS): There is a view that SDS holds the key to social inclusion, with its potential to divert children away from segregated settings and formal services and into flexible, mainstream opportunities of their own choosing, supported by people of or near their own age. SDS approach have already raised warning flags about unregulated Personal Assistants, variable quality of care, a risk that professionals take the lead.

Short breaks: Short breaks can also offer children flexible, mainstream community based activities on a one to one basis or with other young people. Barriers associated with short breaks include shortage of provision and crisis use of respite care, the latter likely to be in residential settings with which a child may not be familiar. There is also a potential conflict between parents' desire (and sometimes need) for a break and children's ability to choose if, when and where they have a break. Hence the need for flexible, child-centred short breaks and an increase in funding to support this.

Transition to adulthood: Of the various policy areas reviewed, transition to adulthood/ adult services is perhaps the most problematic. It is difficult for families and sometimes professionals to map a clear path through the raft of

policy initiatives in this area and to understand how these join up. The lack of a concise policy guide setting out service providers' responsibilities and young people's rights is a barrier to smooth transition.

3.4 Conclusion

To conclude, this section outlines the legal and policy context in which this study is based. It affirms the statutory responsibility on local authorities (executed through social work and education) to support children in need (child with autism in this study) and their families to optimise their quality of life experiences. It provides a rationale for exploring the current provision of services from social work for children with autism and their families. It has highlighted some key themes: social work service provision for around the needs of children with autism and their families which has been explored further in the data collection process.

Chapter 4: Literature Review

4.1 Introduction

The purpose of the literature review is to position this research study in the Scottish context exploring the quality of life experiences of parents of children with autism . The review initially focuses on the general issues of parenting, and then moves on to explore the specific issues related to parenting a child with disability and the different disability models. It then narrows down to the impact of living with a child with autism on their parent's lives and also attempt to summarise the help available for children with autism and their families.

Given this research study utilises a grounded theory approach, the initial focus of the literature review was to frame the argument for this research study and inform the development of data collection tools. It was necessary at this stage to maintain the balance of knowing 'just enough' and be open to the data emerging from the field. The review of literature presented below was completed during the period of 2007 to 2010 after which I proceeded to the data collection stage which commenced in 2011 and was completed in 2012. Hence, majority of the literature gathered was published during the period of 1980 to 2010. The first stage of the literature review commenced by looking for articles and studies using 'keyword' search. The following keywords were used to search for relevant articles and research studies - 'autism', 'parenting', 'disability', 'quality of life', 'social work services'. In the second stage, I reviewed the abstracts to wean out any literature that may not be directly linked to the topic of research interest or is duplicated in the search. In the third and final stage of the review, I analysed the literature and explored the gaps in literature that transpired into the arguments for undertaking this research study.

A systematic review of literature was undertaken post the data collection with the view to locate the grounded theory in literature. This covered more up-to-

date material in literature (ranging from 2010 to 2015) and will precede the discussion chapter that follows later (see chapter 10).

The first section that follows is about parenting.

4.2 Parenting

One of the most important and enjoyable, but also challenging phases, in the life cycle of a human is parenting. Parents have the inherent responsibility and duty to 'care' for their children. Becoming a parent is considered a highly significant transition in an individual's life and family life. Almost all of the literature on the transition to parenthood invariably focuses on the arrival of the first child; however, given that every child necessitates adjustment within a pre-existing relationship, it is vital that the same be acknowledged about the arrival of further children. This transition in a person's life can be seen as occurring in several phases; starting with the decision to have a baby and subsequent efforts to become pregnant, or else upon the discovery of an unplanned pregnancy. After this comes the stages of pregnancy itself; the birth; the settling period immediately post-partum; and finally the child's developmental phases up until around 2 years of age (Polemeneo, 2000). It is during this time that parents need to make many adjustments to their individual lives, within their couple relationship, and in their relationship with others such as family, friends and midwives (Holmes et al., 2013) This involves major changes in the various roles parents play, their outlook towards these relationships and how needs are prioritised within them. Each phase is portrayed as posing potential challenges for couples. An understanding of the nature of these challenges and their separate characteristics is essential in the development of any policy or practice that aims to promote healthy social and emotional development in infants in early life. This understanding is also vital for promoting positive co-parenting, and supporting couple relationships in general.

4.2.1 Factors that Affect the Parenting Experience

Child's Gender

Several studies on this topic have reported that the birth of a girl rather than a boy is linked to greater decline in overall satisfaction for parents (Cox et al., 1999; Doss et al., 2009). This is particularly noted in the case of unplanned daughters. One explanation for the latter is that generally fathers feel more excited to engage with boys, and so the mother's expectation that the father will be active in bringing up the child is dampened if the offspring is a girl, resulting in relationship breakdown.

Child's Temperament

The extent to which a new baby is irritable and fussy, how demanding they are and how easily they develop regular patterns for food and sleep have a huge effect on the experience of parenting (Meijer et al., 2007). If the total experience is felt as more negative than positive, the ensuing impaired mood and impatience can lead to a deterioration of parents' shared balance, communication and family experience in general.

Child's Illness and Disability

Health problems affecting the infant and the consequent time spent in neonatal wards is distressing for parents (Fowlie & McHaffie, 2004). However, research in this area is scarce. Parents of children with special needs report greater pressure on their relationship than do other parents (Glenn, 2007). The parents of a child with special needs feel the burden of increased demands and responsibilities in providing care, extra financial costs related to specialist care and also possible grief at the loss of their cherished dream for a healthy normal baby. These are all contributing factors in their distress.

Parental Fatigue

The various demands of parenthood, such as the increased levels of physical exertion, exposure to more noise, added time and energy inputs often lead to a state of fatigue. This weariness presents a great obstacle to parental communication and leads to decline in parents' relationship satisfaction (Meijer et al., 2007). Mothers and fathers experience similar levels of fatigue after having a new baby (Elek et al., 2002). Parents notice that they are less able to regulate their emotions, less constructive in leading conversations on small issues and more unforgiving as a result of this constant state of fatigue (Kluwer, 2010).

4.2.2 Remarks

The literature on parenting does suggest that parenting a child is one of the most significant transitions in a person's life. It is an accepted fact that most people will become a parent at some point in their life. The official statistics for the year 2012 for England and Wales reveal that 81% of women have given birth to a child by the time they reach age 45 (Office of National Statistics, 2013). In the case of men, this figure is similar: 78–81% have been a father to a child by this age (Modern Fatherhood Institute, 2013). It appears that the whole parenting experience is significantly affected by an array of factors among which disability or illness of the child is highlighted as a particularly stressful factor in terms of the parenting experience. The discussion that follows is an attempt to decipher how a child with disability is interpreted in the research world.

4.3 Disability: Models, Perspectives and Framework

The predominant discourse on disability has been that of an individual/medical model, which largely consign the 'problem' of disability to a deficit within the individual. Humankind's history reveals a society laden with stigma, discrimination and attitudinal and environmental barriers; individuals with disabilities have struggled to live full and productive lives as

independently as possible in such a society. Persons with disabilities have been regarded as ill-equipped for society, as sick, as functionally limited and as unable to work by most legislation, policies and practices (Brooks, 1991; Brzuzy, 1997; Hahn, 1983; Mackelprang & Salsgiver, 1996; Quinn, 1995). Most studies in recent decades have vigorously contested this notion of disability as a compartmentalised, individual problem as being a deficient and erroneous conceptualisation of the lived experiences of people with disabilities (Asch & Fine, 1988; Barton, 1988; Davis, 1997a; Fleischer & Zames, 2001; Oliver, 1983; Pfeiffer, 1992, 1998; Priestley, 1999; Sapey & Hewitt, 1991). Since the 1970s we have seen a growth of self-organisation of people with disabilities and this has led to a re-definition of disability as a social construct. Nowadays it is widely seen that social, cultural, political and environmental barriers are more disabling than are physical or cognitive disabilities (Oliver, 1996; Priestley, 1999).

4.3.1 Social and Cultural Constructions of Disability

In recent times, there has been a shift towards the application of a social constructionist approach for disability (Borden, 1992; Brzuzy, 1997; Ringma & Brown, 1991). Witkin (1990, p. 38) describes constructionism as a theory that seeks to 'elucidate the socio-historical context and ongoing social dynamic of descriptions, explanations, and accountings of reality'. Central to this concept of social constructionism is that theory and the dominant forms of understanding are not definite conclusions in themselves, and that knowledge is not an objective entity; rather, it is a social creation (Levine, 1997). Constructionism scrutinises the ways in which knowledge is historically situated and embedded in cultural values and assumptions, socio-cultural norms and language (Patterson, 1997). From the constructionist viewpoint, language is seen to serve as a mechanism for producing meaning and generating knowledge, rather than a representation of an objective 'truth'. Constructionism as an epistemology provides a different perspective to the commonly seen narrative of knowledge as the main embodiment of

positivism and scientific inquiry in a monolithic landscape; thereby contributing a liberating quality to the social sciences (Witkin, 1990).

Social constructionism can help to elucidate the contemporary conceptualisations of disability. The most individualistic accounts of disability and personal tragedy fail to recognise that even the most tangible of disorders, such as visual impairment, do not exist independently of culture and society. However, the contemporary language of disability has proponents who analyse it in a different way, saying that the individualistic representations of personal tragedy suggest that disability and impairment exist independently of cultural, historical or other contexts (Brzuzy, 1997). The constructionist perspective contests this concept and views a disability-related impairment as arising from the relationship between the person with a disability and their socio-cultural environment. In this model, the environment, rather than the individual, is seen as the primary target of intervention. It is evident that this framework is diametrically opposed to the position taken by social work education regarding disability, where the emphasis is on rehabilitation, adaptation and mitigation (Gilson & DePoy, 2002).

In light of the various cultural studies undertaken to date, the cultural construction of disability questions the prevalent image of the modern human being as this enlightened, rational and progressive actor in society. It scrutinises contemporary knowledge to dissect the indirect and allusive assumptions about disability and people with disabilities. A large number of ethnographic studies undertaken by anthropologists have examined how this subjective experience of disability, and both explicit and implicit assumptions, shape our understanding of the disabled experience (e.g., Groce & Scheer, 1990; Ingstad & Reynolds-Whyte, 1995; McDermott & Varenne, 1996).

The experience of disability also varies across cultures and frontiers. Edgerton (1970, 1985), who is a pioneer in this field, highlights differing attitudes towards people with impairments in non-Western cultures. This could range from negative discrimination to acceptance and to positive attribution of supernatural powers. Locust (1985) examines differences in

Native American beliefs about 'un wellness' across disparate cultures such as the Hopi, Apache, Yagui and Navajo. A classic example is that of Piki Maker, a proficient bread maker whose physical differences in back structure and arm length are considered assets by her community that allow her to produce bread at a more efficient rate than anyone else in the tribe.

Thus, it is clear that disability is not one dimensional and is hardly a unitary concept. In certain cultures an individual cannot be 'disabled' because 'disability' as a distinct category does not exist. The term 'disabled' does not even have an original translated word in many languages, although there are terms for people with visual, hearing and cognitive impairments (Ingstad & Reynolds-Whyte, 1995). This absence of a universal definition for disability throughout our history and across various cultures indicates a tenuous relationship between the disabled individual and society.

4.3.2 Disability from Differing Perspectives

The widespread and dominant view of disability has been the medical model, which categorises disability as a functional limitation, as an individual 'problem', 'pathology', 'dysfunction' or 'deviance' (Brzuzy, 1997; Finkelstein, 1991). According to Oliver (1996), the individual/medical model pinpoints the 'problem' of disability within the individual and concludes that functional limitations or psychological losses arise naturally from the individual deficit. This concept is also known as the personal tragedy theory of disability, which postulates that disability is a natural disadvantage suffered by disabled individuals when implanted in competitive social situations. Rather than exploring disability as closely linked to social, cultural and political environments of the disabled individual, the medical or personal tragedy framework automatically infers that the disabled individual is plagued by deficits and is in need of medical 'fixing' (Quinn, 1995).

The social narrative of disability also addresses the issue of grief, loss and bereavement associated with mental and physical disability. Disabled

individuals are noted to be suffering subjects, characterised by calamitous changes and crises for both themselves and their families.

Others have examined disability from an ecological or psychosocial perspective. For example, Mackelprang and Hepworth (1987) suggest the importance of extending the medical perspective of disability to social factors such as stigma; the societal architecture and awareness of a social structure constructed by the non-disabled majority. Under this framework, the extent of disability is mutually determined by transactions between people and their environments, rather than within the individual alone. Social workers have always enunciated the importance of inclusion and accommodation for individuals with disabilities; however, they have largely stayed away from active involvement in the disability rights movement that has been initiated by people with disabilities and their advocates.

Another strand in disability is viewing it from empowerment, strengths and resilience perspectives (Burack-Weiss, 1991; Saleebey, 1997). Initial conceptualisation of this framework was by Solomon (1976) and since then others have contributed to this empowerment approach. This specifically addresses increasing the social, economic and political influence of oppressed groups in relation to privileged sections of society (Hahn, 2005). Social workers in recent decades have been inspired by this empowerment perspective to develop collaborations with oppressed groups such as persons of colour and persons living in poverty (May, 2005). Unfortunately, this empowerment theory has had a miniscule effect on real-life problems of people with disabilities who are more affected by the mainstream medical model than are other vulnerable populations (Felske, 1994; Linton, 1998; Morris, 1991; Moxley, 1992; Zola, 1989). Empowerment has tended to focus on short-term interventions that purportedly produce permanent benefits; however, some studies (e.g., Gillam, 1998; Hiranandani, 1999) reveal empowerment of disadvantaged groups may be transitory in the current polarised socio-political atmosphere with its skewed power relations.

The strengths perspective of disability presumes that strengths, such as talents, capacities, knowledge and resources are present in all individuals and communities. With respect to disability, the strengths perspective views disability as an opportunity for growth as well as a source of impairment. Social work practice based on this concept attempts to take into account the abilities of people with disabilities instead of giving undue importance to their disabilities in service planning, delivery and assessment (Raske, 2005). The resiliency model, which has similarities to the strengths concept, endorses the inherent strengths in individuals and families who have overcome environmental, social and personal barriers despite oppression and discrimination (Bernard, 1991).

However, there is some danger with this resiliency perspective as people with disabilities who 'overcome' their disability are seen as 'disabled heroes'. It is patently clear that disabled heroes can be inspiring to people with disabilities and comforting to the able-bodied, but at the same time they may eternalise the false impression that anyone can 'overcome' disability and accomplish unusual feats. As Wendell (1997) points out, most of these high-achieving disabled heroes have exceptional social, economic and physical resources and backing, to which most people with disabilities do not have access. This image of the irrepressible disabled hero creates an ideal that most disabled people cannot achieve nor even aspire to at times, thereby creating a secluded feeling and increasing the feeling of 'otherness' of the majority of people with disabilities.

However, overall in the recent years, with evolving new concepts on disability, the traditional medical model of disability has been challenged and studies have emerged from various branches of humanities and social sciences, such as anthropology, political science, rhetoric, history, literary and cultural criticism and disability (Barnes, Mercer & Shakespeare, 1999).

4.3.3 A Social Model of Disability

The social model of disability was initially introduced into the public space in the UK in a 1976 statement by the Union of the Physically Impaired Against Segregation (UPIAS, 1976). The model has since been discussed extensively by Finkelstein (1980), Oliver (1983, 1990, 1996) and Corker (2000). Unlike the medical model's slender focus on functional limitations, the problem according to the social model, is 'society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation' (Oliver, 1996, p. 32). According to the social model, disability encompasses all factors that impose limitations on people with disabilities, ranging from pessimistic social attitudes to institutional discrimination; from inaccessible public buildings to impractical and useless transport systems; from separated and discriminative education to exclusion in work arrangements; and so on.

Some people with physical impairments experience suffer from varying levels of pain and struggle on a daily basis to meet their physical needs, and that this cannot be eliminated or mitigated. Never-the-less, it has to be recognised that many of the barriers that people with disabilities face are the direct and indirect consequences of having those physical impairments under the existing inflexible social and economic systems. These social and economic systems can—but are not willing to—accommodate disabled people's physical conditions or assimilate their struggles into the cultural concept of everyday life (Asch & Fine, 1988).

The social model aims at changing society to accommodate people with disabilities; more importantly, it is not asking to modify or rectify disabilities to accommodate them in society. It always upholds the view that people with disability have the same right to fully participate in the activities and decision making of modern society as able-do citizens.

The social model of disability is now the internationally accepted way to view and address 'disability'. The United Nations *Convention on the Rights of*

Persons with Disabilities (CRPD), which was adopted by the United Nations General Assembly on 13 December 2006, is based on this model. Acceptance of this social model by the United Nations marks an official paradigm shift that helps in promoting positive attitudes towards people with disability. It is evident that people with disability are not to be considered 'objects' of charity, social protection or medical treatment, but are real people with human rights, capable of claiming those rights and able to make decisions for their own lives based on their free and informed consent and be active members of society.

To summarise, impairment is a medical condition that may lead to disability; whereas disability is the net result of the interaction between the impairments of these people and existing barriers in the physical, attitudinal, communication and social environment. In this context the following analogy is self-explanatory: for a person with disability it is not the inability to walk that prevents them from entering a building by themselves; it is the stairs that are inaccessible that prevent a wheelchair user from entering that building.

4.3.4 Marxist Perspective of Disability

Karl Marx believed that to understand any human society, it is vital to consider the material aspects of human existence, which means that we need to understand the economics of producing the basic necessities of life. This economic mode of producing the basic things of life is so important that it influences other aspects of life, such as political organisation, ideology, religion and culture.

Marxist writers analyse disability as a social issue that is directly linked to the changing mode of production. In their analysis, the characterisation of disability and other social problems is influenced by both the economic and social structures and the core values of the particular mode of production existing in that period; thus, definitions and attitudes towards disability can change according to the economic mode of production (Oliver, 1990; Priestley, 1999). Oliver (1990) believes that the individualised medical

approach to disability came to the fore because of the demand for a workforce that is physically and intellectually able to survive the harsh realities of industrialisation.

Oliver claims that in a feudal society, people with disabilities were not excluded from participation in the process of production; even in those scenarios where the disabled person could not fully participate, their contributions were still included and they were not segregated from the rest of society. However, with the development of capitalism there was widespread changes in organisation of labour, leading to profound implications for social relations, family life and attitudes. Disability was there long before the advent of capitalism, but with capitalism, it clearly took a different form of social relations: industrial capitalism excluded disabled people from equal participation in the labour force, so they became the outcasts (Priestley, 1999).

4.3.5 Welfare Capitalism

The growing number of injured personnel and those with disabilities pouring from the battlefields of World War I led to the development of rehabilitation efforts in Europe and the US; this group of newly disabled people resulted in a paradigm shift in the way society approached and dealt with disability (Stiker, 1982). This influx of disabled war veterans led to the growth of institutional welfare arrangements, to the emergence of rehabilitation as a medical and paramedical specialisation and, most importantly, to development of disability as a concern of the state (Gritzer & Arluke, 1985). Even though rehabilitation initially was aimed at personnel who were disabled, secondary to battlefield injuries over time these benefits and considerations were applied to all congenital and acquired impairments. The development of rehabilitation and intervention in disability by the state in the twentieth century was accompanied by legislation, administrative procedures, welfare institutions, professional specialisations, medical diagnoses and business interests (Ingstad & Reynolds-Whyte, 1995). The state had to find a

way to determine who is entitled to the rights of financial support and services; as this was based on diagnoses, the onus fell on medical professionals. What in reality was a political issue of redistribution, that involved separating the deserving from the undeserving therefore became a clinical problem.

With the expansion of government control and disability budgets, a population that is ageing, an increase in chronic diseases and the growth of the health insurance industry, disability has become big business (Albrecht, 1992; Finkelstein, 1991). In this new world, disability has been institutionalised and the goods and services for rehabilitation have become more like commodities in an ever-expanding market. Strangely as a result of this, disabled people have become consumers with an identity and have formed groups as users of services.

To summarise, it can be argued that 'in late-capitalist countries disability exists and is produced by the state, legal, educational, economic and biomedical institutions. A person's identity, notions of citizenship, value lost through impairment and added through rehabilitation are shaped by these institutions' (Ingstad & Reynolds-Whyte, 1995, p. 10). This demonstrates how the definition of disability can be affected and related to the existing economic organisation and political contexts in a particular historical period.

4.3.6 Normalcy

Foucault tried to analyse medical concepts of disease and 'madness' through the centuries by examining the way the human body was viewed by corresponding societies (Foucault, 1970, 1973, 1977). He argued that the new science of medicine—which can be traced back to the eighteenth and early nineteenth centuries—assumed a 'normalising gaze' on the human body, thereby defining new boundaries between the 'normal' and the 'abnormal'. As a result of this delineation between normal and abnormal, the new sciences became a device for scaling and measuring physical and mental capacities against set standardised norms.

Davis (1997b) notes that disability was viewed in an entirely different way before the eighteenth century. Disability, as we are familiar with it, entered the public domain with the industrialisation and wars of the late eighteenth and the nineteenth century. He also notes that the words 'normal', 'normalcy', 'normality', 'norm', 'average' and 'abnormal' all entered the English language between 1840 and 1860. Davis tries to use statistics to gain more understanding of the concept of disability. Normal, average and deviations from the average are basic elements of statistics. Concepts of the norm cannot exist without the concept of deviations. Depicting all the people in a population on a graph will show that the shape created is the standard bell-shaped curve; that is, the normal distribution. People whose abilities and features deviate from 'the norm' will lie at the extremes of this distribution and they will be the people with disability. It follows that a society that runs on the concept of the norm or the average will consider disabled people as deviants (Davis, 1997b).

In the late eighteenth century there was an obsession with measurements and statistics that resulted in various concepts of hierarchies of physical, psychological and cultural differences: 'people could be conveniently divided and classified not merely in terms of geographical origin or color but equally by virtue of cranial capacity and shape' (Solomos & Back, 1996, p. 34). In this context arose Charles Darwin's theory in which disabled people were seen as the defective ones in the cycle of evolution who would be eliminated by the process of natural selection (Baynton, 1997).

There has been an ongoing tussle regarding this definition of normalcy and the arbitrary nature by which certain professionals are allowed to draw that line and dictate the society. Amundson has undertaken extensive work on this and considers that the concept of 'normal' is highly fictitious and that classification into normal and abnormal in medical science is neither objective nor scientific. He suspects that these descriptions are mere slogans by a certain class of the population to retain their dominance. Thus, he argues that the disadvantages suffered by disabled people, who are labelled

abnormal, do not come from the biological sciences, but from unwritten societal judgments and refusal to accept certain biological variances (Amundson, 2000).

Contemporary disability theorists (e.g., Amundson, 2000; Davis, 1997b) recommend that we analyse in detail the construct of normalcy in a society rather than focusing our study on a disabled person or their disability.

4.3.7 Feminist Disability Theories

To the above-mentioned cauldron of disability concepts, feminist-based theories were added in the late 1980s and 1990s, as the proponents were keen to understand how gender had marginalised women (Cummerton, 1986; Fraser & Gordon, 1994; Harding, 1997). Through the social model we have identified that disability is a disadvantage because of social, cultural, attitudinal and environmental barriers. This is similar to the case for females because of the socio-cultural context that has evolved over the centuries. Thus it seems that gender and disability are, in fact, inextricably linked.

Disability and gender problems are not present biologically; but the biological reality of impairment and gender results in them being socially constructed (Wendell, 1996). Thus in essence, both females and the disabled body are projected within the cultural milieu as deviant and inferior. Both are excluded from full participation in public, social and economic life. The female gender and the person with disability are shown to be inferior with respect to the norms of the society, which have been arbitrarily defined as those of an upper class, able-bodied white male (Garland-Thomson, 1997b). These pre-written body concepts have been used to create the artificial hierarchies in our everyday lives whether they be social, political or economic.

Because of set norms, society has tried to idealise physical and mental capacities, which has resulted in marginalisation of the disabled person. The disabled person is not only undervalued for their bodily disparity from the set

norm, but serves as a constant reminder to the able-bodied of undesirable that they are trying to avoid, forget and ignore (Wendell, 1997).

4.3.8 Social–Relational Model of Disability

Disabled feminists such as Jenny Morris (1992), Liz Crow (1995) and Sally French (1993) question the rigid shibboleth-like view taken by the social model of disability. They argue that presenting disability in an uncomplicated manner to convince a very sceptical world that disability can be reduced or eliminated by changing society results in people forgetting the fact that there are those with genuine impairments and pain who need support. Jenny Morris's very popular and influential book, *Pride Against Prejudice* (1991) showcases this argument.

It was at this time that Carol Thomas came up with the relational model of disability incorporating various elements from the social model and removing some concepts from it. According to Thomas, the social model could be viewed in two ways: in the 'social–relational' sense she promotes or in a 'proprietary' sense. In relation to the former, she writes, 'Disability expresses an unequal social relationship between those who are impaired and those who are unimpaired' (Thomas, 1999, p. 40). So this model views disability through the prism of this relationship. In contrast, Thomas explains the 'proprietary' approach as meaning 'disability is a property of the person with impairment ... Disability is then causally attributed to social factors' (Thomas, 1999, pp. 40–41). The problem with the proprietary model is that it makes disability a personal issue and seeks to find a social cause for the restriction caused by impairment. However, as a matter of fact in some cases there might not be a social cause for that restriction and the single cause for the restriction might be the impairment (Thomas, 1999, pp. 40–41). In the relational model advocated by Thomas, these non-socially imposed restrictions are also incorporated and are called 'impairment effects'. Thus, the approach of Thomas is a bipartite one including the socio-structural barriers that place limits on disabled people's inclusion, thus damaging first

the psycho-emotional wellbeing of people with impairments and second, the non-socially imposed restrictions. Thomas believes that this model will help in promoting a full and complete analysis of the experiences of disabled people.

4.3.9 International Classification of Functioning, Disability and Health Model

The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) offers a potential way forward for understanding and intervening in the field of disability. It is a bio-psycho-social model that is a compromise between individual medical approaches and structural social models. The ICF model has been developed for use in a variety of settings. It examines the functioning of social services including welfare benefits and accessibility of buildings. It has a classification system with a complex numerical coding system and operational definitions at each level. Disability, according to the ICF model is the result of an interaction of an underlying health condition, personal factors (e.g., coping style) and environmental factors (e.g., architectural barriers, employment policy, stigma). There is a range of options for reducing levels of disability in both individuals and in society. From a visually impaired person's perspective, this model aims to combat prejudice and social stigma and at the same time seeks creation of accessible workplaces and broadcast media.

As in any system, there are limitations and difficulties in the ICF schema. It aims to cover all forms of disability and health conditions. One problem with this universal approach is that there is no clear distinction between a temporary illness and a long-term chronic disease or impairment. From a social perspective this is important, as a temporary illness will not usually affect the person's social and psychological identity whereas the latter generally will.

4.3.10 Remarks

It has to be acknowledged that the majority of the social science research literature on disability has gravitated towards the social model or the social-relational model of disability, perhaps because of its simplistic framework and its capacity to present disability and its effects on the day-to-day lives of people. Either of the two models will be beneficial as a framework for this research, with its focus on parents' experiences of a child with disability (autism).

Disability is a multidimensional, highly complex variable; it cuts across the range of political, social and cultural agendas. Children with disability do not represent a homogenous group, nor are they a cohesive collective with a common identity and interests (Corker et al., 1999). There are many subgroups and each may experience disability in different ways. For example, ethnicity and cultural background can influence the experience of childhood disability (Hussein et al., 2002). The effect of social class on the experience of disability in childhood has been pointed out by Eric Emerson and Chris Hatton (2007). There is research to substantiate that poverty and living in areas of high social deprivation has resulted in increased rates of mental health problems in children and adolescents with a learning disability. According to Emerson (2003), another factor that may influence the experience of childhood disability is gender. Disabled children living in the Global South also experience disability differently to those in the Global North (Filmer, 2008).

Children who have acquired their impairment or were born with their impairment, and have physical or sensory impairments, mental health issues or intellectual disability (ID) or a combination may all experience different outcomes and have differing needs. That is, they have different implications for health and individual capacity. Different impairments also produce different responses from the broader cultural and social milieu. Further, children who are disabled experience limitations that may have little to do with social organisation—what Aberley (1996) terms 'real inferiority'. These

limitations make it impossible for them to participate effectively in the community, not least because they have a narrower margin of health. All disabled children have different needs and it is difficult to develop a 'one size fits all' model, research agenda or policies to meet these needs.

Disabled feminists such as Morris (1991), French (1993) and Crow (1992) were among the first to highlight the social model neglect of individual experience of impairment: 'As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives. We must find a way to integrate them into our whole experience and identity for the sake of our physical and emotional well-being, and, subsequently, for our capacity to work against Disability' (Crow, 1992, p. 7).

Connors and Stalker (2003, 2007) were among the first to apply a social-relational approach to the study of disabled childhood. They conclude that the 'social-relational approach can help in our understanding of disabled children's experiences' (2007, p. 31).

The next section reviews the literature on parenting a child with disability.

4.4 Parenting a Child with Disability

According to the *Disability Discrimination Act 1995* (replaced by the *Equality Act 2010*), 'a person has a disability if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'. The 'Guidance Notes' accompanying the *Disability Discrimination Act 1995* indicate that disability can be caused by various types of impairments such as sensory impairments (e.g., affecting vision or hearing), impairments that present intermittently (e.g., rheumatoid arthritis, depression, epilepsy), progressive impairments (e.g., dementia, muscular dystrophy), organ-specific impairments (e.g., asthma, heart disease), learning disabilities (e.g., Down syndrome), learning or developmental difficulties (e.g., dyslexia, ASDs), mental illness (e.g.,

schizophrenia, bipolar disorders), communication impairments (e.g., stammering) or impairments produced by injury to the body or brain.

The *Disability Discrimination Act 1995* highlights the fact that autism is recognised, along with other conditions, as a disability in the legal and political fabric of the UK. This information is critical for the current research, being based in Scotland.

4.4.1 Effect of a Child with Disability on Parents

Bringing up a child with or without disability can be stressful. Pelchat et al. (1999) argue that parents of disabled children suffer from higher levels of stress than do parents of able-bodied children (Pelchat et al., 1999; Woolfson, 2004).

Analysing the various studies that have examined the effect of children with disabilities on families, Summers et al. (2005) note three broad effects—stress, depression and caregiver burden—arising from child's disability, the effect the child's disability has on the functioning of the family unit and eco-cultural adaptations to family routines because of the disability of the child.

Multiple studies have revealed that caring for a child or young person with disabilities places manifold demands on parents, which in turn lead to stress and burden (Brannan et al., 1997; Egan & Walsh 2001; McGilloway et al., 1995; Hassall et al., 2005; Kenny & McGilloway, 2007; Salovita et al., 2003; Shearn & Todd, 2000).

The effect a disabled child has on the overall functioning of the family has also been studied more objectively with the help of various family adaptability and cohesion scales (Olson et al., 1992; Summers et al., 2005) and family environment scales (Moss & Moss, 1986; Summers et al., 2005). These scales evaluate the functioning of the family based on parameters relating to adaptability, cohesion, social desirability and environmental characteristics.

It seems that some eco-cultural adaptations are also made by the families voluntarily and involuntarily, affecting their daily routines and ways of

socialising to accommodate the disabled child (Diamond & Kontos, 2004; Summers et al., 2005).

Within the disability group, parents of children with ID have higher levels of parenting stress than parents of typically growing children with physical disability (Douma et al., 2006; Floyd & Gallagher, 1997; Hastings, 2002; Hastings & Beck, 2004). After analysing the sample used in these studies, I was able to infer that the definition of developmental disabilities and learning disabilities encompasses a wide range of disabilities such as Down syndrome, autism, cerebral palsy and learning disability (mild, moderate, severe). This process further identified a gap in the literature with respect to research that focuses specifically on autism (one of the several conditions in the autism spectrum) as a disability, and how it affects the family.

In most cases, the birth of a child with learning disability has a profound effect on the family and mandates that one or more family members (usually parent(s)) take on the role of 'carer(s)' (Kenny & McGilloway, 2007).

Another term that is widely used in such scenarios is 'caregiver strain'. This is defined as the 'demands, responsibilities, difficulties, and negative psychic consequences of caring for relatives with special needs' (Brannan et al., 1997; Kenny & McGilloway, 2007). These researchers further divide caregiver strain into objective strain (the observable events arising from a child's problems/behaviour) and subjective strain (the emotional strain of caring). They also examine the age of individuals affected by these disabilities and note that the subjective strain among families caring for children with disabilities is much more pronounced than in those caring for adults with disabilities. Some of the sources of caregiver strain in adults are conflicts arising around issues of impairment, financial strain and restrictions to social and recreational life (Kenny & McGilloway, 2007; Pearlin et al., 1990).

These studies demonstrate the significant stress from which carers suffer in bringing up a child with disability, which is exemplified by the coining of the

new term of *caregiver strain* to describe it. These concepts are extremely important for the current study, which examines this topic through a specific disability, namely autism.

4.4.2 Factors Affecting Caregiving

Time and Energy

Caring for a child who has a developmental disability will invariably mean expending substantial time and energy, performing unpleasant tasks and experiencing frequent interruption to family routines (Plant & Sanders, 2007; Seltzer & Heller, 1997; Shultz & Quittner, 1998). Plant and Sanders (2007) analysed relevant studies to date on this topic to identify the main variables that make caregiving a very difficult and stressful job. Those variables include difficulty in completing caregiving tasks, time taken to complete the task, problematic behaviour of the child and level of disability of the child.

Problems of the Child

Unfortunately, a sizeable proportion of children with disabilities exhibit difficult features that add to the caregiving stress. A community survey of children with severe ID and their families found that 29% of children in the sample with severe learning disabilities showed aggression towards others and 27% presented self-injurious behaviour (Hoare et al., 1998). Food preferences resulting in meal-time behaviour problems have also been noted (Levin & Carr, 2001). Certain children have behaviour problems during the night, such as night-waking and difficulty in settling down to sleep. More than 75% of children younger than 16 years with learning disabilities experience sleeping problems (Bartlett, Rooney & Spedding, 1985). Further, it has been noted that such problems tend to persist over a number of years (Quine, 1991). Disrupted sleep and night time behaviour issues result in both parent and child being sleepy during the day. This is not ideal for the child's development and can result in the parent providing minimal guidance to the child about appropriate daytime behaviour (Wiggs & Stores, 1996).

Other Associated Factors

The hardships faced by parents in raising a child with a disability have been noted to result in:

- anxiety, overprotection and rigidity (Lardieri et al., 2000 in Heiman, 2002)
- lower levels of coherence and less emphasis on the growth and development of other family members
- a greater emphasis on control within the family (Heiman, 2002; Margalit & Heiman, 1986).

It is reported that parents of children with disability have more health problems, greater feelings of restriction and higher levels of parental depression than parents of non-disabled children (Heiman, 2002; Quine & Paul, 1985; Roach et al., 1999; Valentine et al., 1998).

The next section outlines the experience of parenting a child with autism.

4.4.3 Parenting a Child with Autism

It is evident that parents of children with autism and other learning disabilities (e.g., Down syndrome) are more stressed in raising their children than are parents of non-disabled children (Blacher et al., 2006; Mungo et al., 2007). In addition, parents of children with other ID show less stress than parents of children with autism (Olsson & Hwang, 2003; Rodrigue et al., 1990; Sanders & Morgan, 1997). This increased stress burden seen in parents of children with autism has been attributed to the specific characteristics that are encountered in an autistic child compared with children with other developmental disabilities (Kasari & Sigman, 1997). Unfortunately, the presence of autism within a family brings myriad challenges. It is postulated that 'families of a child with ASD are excluded from "normal life" mainly due to the burden of care that significantly affects their social life, parental careers, mental health and marital relationships' (PHIS, 2001, p. 51).

Hayes and Watson (2013) conducted a meta-analysis of 15 studies (from 1989 to 2010) that compare the burden of parenting stress for parents of children with or without ASD. They found that the study evidence affirmed the prevailing notion that parenting and raising a child with ASD was much more stressful than parenting typically developing children or children with other disabilities (e.g., ID, cerebral palsy, Down syndrome, fragile X syndrome, foetal alcohol syndrome). Although the meta-analysis confirmed the prevailing notion, it also identified gaps in the literature. The authors agreed with Seltzer et al. (2004) for the need for further studies to explore the specific child characteristics, the biological and psychological vulnerability of both parents and children in these groups, and the relevant socio-economic demographics of the families. None of the individual studies detailed the difference in stress level between mothers and fathers in the same group. The available data indicate that the majority of research has been conducted on mothers only, or on both parents but without differentiating between mothers and fathers.

One challenge is the number of father participants included in research. There has been a call for further studies to understand whether there was a difference in the level of stress and negative effects of parenting an autistic child between father and mother groups. It has also been acknowledged and highlighted that as a group, children with ASD are highly heterogeneous and researchers commonly include the full range of ASD diagnoses (autism, Asperger syndrome, PDD) as one homogeneous category, which affects the validity of the findings because of insufficient discussion on its variability. It is noteworthy that none of the studies included in the meta-analysis were based in Scotland. Indeed it is difficult to identify research in a Scottish context, although several autism studies have been done in other parts of the UK (Cohen; 2005; Wing, 1991).

The conclusions of Hayes and Watson (2013) are quite important with respect to the current study, which aims to explore areas not touched upon in previous studies.

The next part of the literature review examines how parenting an autistic child affects the QOL experience of parents.

4.5 Quality of Life

QOL is a term used in various disciplines of science and humanities and even in day-to-day life—from advertising executives to politicians. Although it is used in everyday language, it is a complex, multidimensional and multi-layered concept that continues to defy consensual definition; its usage across various platforms may well be the reason for this lack of consensus (Farquhar, 1995). The terminology acquires more importance in health sciences but even in that context it lacks an accepted definition. As it is open to wide, varied interpretations, some authors have decided not to define it but to attempt to measure the related elements that constitute this complex subject (Bowling, 1995; King et al., 1997; Mast, 1995; Meeberg, 1993).

If QOL is such a problematic and discord-creating concept, some might question why we need to bother with it. However, we do bother with it because it matters to all of us, whichever sphere of life we are in; as is beautifully summarised by Cohen et al. (1996) in their study of patients with cancer. Rather than omitting it from public discourse, it is vital that we discuss and research QOL, so that we can come to a common understanding of this evolving phenomenon (King et al., 1997).

I have tried used the conceptual analysis method outlined by Walker and Avant (1995) to explore the concept of QOL. Examining various dictionary definitions for this term provides a useful measure of how its meaning has evolved over recent decades. In 1987, QOL was described as an adjective meaning ‘affecting the quality of urban life’ (Random House Dictionary, 1987). In 1992, QOL was defined as a noun meaning ‘the degree of emotional, intellectual, or cultural satisfaction in a person’s everyday life as distinct from the degree of material comfort’ (The American Heritage Dictionary, 1992). A later definition of the word *quality* provides yet another view: ‘Quality: (n.) ... 8a. Originally: the nature, kind, or character (of

something). Later: the standard or nature of something as measured against other things of a similar kind; the degree of excellence possessed by a thing' (The Oxford English Dictionary, 2009).

4.5.1 Historical Perspective

Day and Jankey (1996) provide a historical outline of the emergence of the QOL concept in their treatise published in the book *Quality of Life in Health Promotion and Rehabilitation: Conceptual Approaches Issues and Applications* (pp. 39–50). In the 1960s, social scientists based in the US noticed a large increase in violence and public disorder despite increased societal wealth. These arguably contradictory events led them to investigate further as it was clear that wealth and economic growth was not the single determinant of happiness and QOL. They began to use various social indicators such as level of education, type of housing and so on to study and if possible mirror the nation's QOL. However, the social indicators selected were wholly dependent on the researcher's own interests and passion, so were biased and flawed.

In the 1970s, there was a change in QOL research and the focus was on psychological indicators like happiness and satisfaction, which represented a more accurate measure of QOL than objective measures of social indicators (level of education, type of housing, etc.).

In the 1980s, notably several gap theories of QOL emerged. The most popular among these was the one in which QOL was most accurately described as the difference between a person's present circumstance and a reference standard to which one compared oneself. The difficulty was in determining the appropriate comparison reference point, as these could be innumerable in many circumstances. However, researchers conventionally have attempted to circumvent this issue by using a reference group, what one considers ideal or what one wants to have as their comparison referents (Bach & Rioux, 1996 in Renwick et al., 1996). Although the concept of QOL has continued to evolve at a fast pace over the past four decades, no single

theory has emerged as pre-eminent; rather, theorists and researchers continue to pursue different paths (Hass, 1998, pp. 728–742).

4.5.2 Defining Quality of Life

As Awad (1999, in Corring & Cook, 2007, pp. 240–244) put it, QOL is ‘deceptively simple and easy to understand yet complex and frequently elusive to define; it can mean different things to different people’. This results in multiple explanations for the concept of QOL depending on the rationale and context of a study; in some instances researchers might combine various aspects, as succinctly described by Robillard (2000): ‘generally, quality of life is seen as the product of the interaction of a number of different domains—social, health, economic, and environmental conditions’. As mentioned previously, many researchers have opted to discuss the indicators used to measure QOL in their study rather than trying to conceptually define QOL (Hass, 1998, pp. 728–742; Velasco et al., 2000, pp. 892–900).

Despite the lack of a consensual definition, the concept of QOL is very popular in a range of research disciplines including healthcare, disability and social work research. Therefore, we may surmise that this concept QOL remains highly contextual and will make most sense within the boundaries of a given research study. As there is no single definition for QOL used by researchers globally, there is a certain degree of freedom for the researcher in how to portray the concept of QOL in their research.

4.5.3 Measuring Quality of Life

QOL is a measure of an individual’s wellbeing that includes multiple domains of functioning and is widely recognised as an important framework to use in the study of developmental disabilities. In this respect, the vital components of QOL conceptualisation were first stated by the Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (Schalock et al., 2002). Researchers in the field later refined the original statements and have suggested several core principles as outlined

here: 'QOL (1) is multidimensional and influenced by personal and environmental actors and their interactions, (2) has the same basic composition for all people, (3) is both subjective and objective, (4) and is enhanced by self-determination, resources, purpose in life, and a sense of belonging' (Cummins, 2005). As mentioned, there is no universal definition for QOL and there are inherent difficulties in reaching one. To complicate matters, a consensus regarding principles that guide the measurement of QOL has also not yet been achieved across disciplines and substantial work remains to reach an agreement on how to best measure QOL (IASSID World Congress, 2004; Verdugo et al., 2005).

Apart from providing security, one of the most important goals of any government is to improve the QOL of its citizens; but how can a particular government know whether the measures they have instituted have improved QOL, and how can they compare the QOL of their citizens with those of another country? The most commonly followed approach is to use QOL indicators, which include measures of at least some of these dimensions: economic wellbeing, health, literacy, environmental quality, freedom, social participation and self-perceived wellbeing or satisfaction (André & Bitondo, 2001). These indicators may also be used by neutral, international observers or researchers to evaluate a country's performance.

Let us review comparative international approaches to measuring QOL. Some indicators are 'objective' or countable, such as Gross Domestic Product (GDP) per capita, infant mortality rate and literacy rate. An alternative group of indicators that are more 'subjective' focus more on individual perceptions of wellbeing or satisfaction. Some QOL approaches use mainly objective indicators, while others focus more on subjective ones.

Objective Approaches

The best known and most widely accepted composite QOL scale (Sharpe & Smith, 2005) is the United Nations Development Program (UNDP) Human Development Index (HDI) (UNDP, 2004). The HDI is calculated in decimal

figures, which makes it easy to compare among contexts. It is a composite statistic of three core aspects of modern life: life expectancy, education and standard of living (per capita income). The indicators used to measure each of these three components changed in 2010 and the respective indicators for each core attribute are now:

- life expectancy, measured as Life expectancy at birth
- education, measured as Mean years of schooling and Expected years of schooling
- standard of living, measured as Gross National Income per capita

Countries are rated on how well they are performing on each component with respect to the range of possible values for that component. UNDP sets minimum and maximum values for each component, which may vary greatly from year to year, and the final HDI is calculated by averaging the ratings of the three components. As it is a comparative rating, a country's HDI score depends on the achievements (or failures) of not only that particular country but also that of other countries. It must be noted that the score cannot be used to chart the progress from year to year of any one country, as the distribution of values for each component change yearly.

Other international composite scales of repute are Prescott–Allen's (2001) Index of the wellbeing of nations and Estes's (1997) Index of social progress (Sharpe & Smith, 2005). All these scales tend to give extremely similar values each time and the fact that they correlate with each other at a level of 0.89 or above is evidence of their measuring abilities (Shackman, Liu & Wang, 2005).

A composite scale like HDI is very useful as an overall indicator. However, there may be problems with its use, as different scales use different indicators or ascribe different weights to indicators, and some surveys may not clearly explain the construction of the composite scale it uses (Giovannini, 2005). Also, single scales may oversimplify the underlying concepts and do not present adequate information about the components to

the layperson (André & Bitand, 2001). Finally, some QOL scales give more importance to income per capita (McGillivray, 2004) and thus may not impart any more useful information than does a simpler economic indicator.

Alternatives

Alternatives to the major objective approaches aim to measure:

- the non-economic aspects of QOL (McGillivray, 2004)
- wellbeing as a hierarchy of needs (Clarke, 2005)
- 'gross national happiness' (Genuine progress indicator, Atlantic).

The refreshing latter approach incorporates social and environmental variables along with economic figures to create a more comprehensive and precise measurement tool.

Over the last three decades, researchers, especially in the social sciences, have aimed to measure the more subjective aspects of QOL and have developed several subjective QOL scales (Camfield, 2005; Diener, 1995; Veenhoven, 2004). Further, there have been studies comparing and contrasting the subjective and objective aspects of QOL and their respective measurement scales (Gasper, 2004). QOL from a subjective perspective has been defined in two main ways:

1. use of various dimensions including perceptions, evaluations and appreciation of life and living conditions, and trust in systems by individual citizens; for example, measures of satisfaction or happiness (Noll, 2005)
2. examination of the outcome of the gap between people's goals and perceived resources in the context of their environment, culture, values, and experiences (Camfield, 2005).

It has long been argued that subjective and objective QOL measures would not be correlated and that there would be disparity, considering the different components/attributes (Gasper, 2004). However, the Economist Intelligence

Unit QOL Index (2005) (or QLI)—now known as the ‘where-to-be-born index’—is highly correlated (at least 0.77) with the objective measures of GDP per capita, infant mortality rate and literacy. The QLI is based on a method that links the results of subjective life satisfaction surveys to the objective determinants of QOL across countries, with a forward-looking element. Another similar scale (Veenhoven, 2004) is correlated at only 0.4–0.5 with the major scales, but 0.74 with the QLI scale.

It is evident that subjective wellbeing (i.e., QOL) is not a unitary concept, but requires different indicators for different aspects (Veenhoven, 2004). Subjective QOL scales are constructed in an entirely different way from objective scales. These scales are, as the label suggests, moulded from an individual’s own point of view. For example, Veenhoven’s (2004) scale uses individual’s perceptions of their life satisfaction and then correlates this against the average responses for each country.

4.5.4 Remarks

The above discussion indicates the availability of several scales or tools to measure objective and subjective QOL of a person, who in this research would be the parent of a child with autism. However, the discussion also identifies that one of the significant vulnerabilities of these scales is a lack of explanation for how these scales have been developed. It is also acknowledged that measuring subjective QOL would require different indicators for different aspects to contextualise a person’s experience; the existing scales may not fully encompass all areas that may be relevant to a person’s QOL experience. Hence, there is scope for the current study to adopt an approach of not utilising existing scales (in contrast to most QOL studies, which use existing scales) and reaching out to the parents of children with autism to define their own QOLs.

4.6 Quality of Life Research and Autism

Although the few studies that have examined QOL for children with autism and their families have employed only small clinical samples, they suggest that families of children with autism report a higher level of family stress and more family problems than families of children with cognitive disabilities, such as Down syndrome (Donovan, 1988; Holroyd & McArthur, 1976), or other medical conditions such as cystic fibrosis (Bouma & Schweitzer, 1990). This may reflect the difficult behavioural profile of many children with ASDs, involving for example, self-injury, tantruming or complex rituals, which can be hard to manage and can interfere with the daily lives of their families. Disruptive behaviours, fixed schedules and the demands of daily life may also make it difficult for families to participate in activities outside the home (Bouma & Schweitzer, 1990; Fox et al., 2002; Howlin, 1988). In a study conducted by Fox et al. (2002), parents indicated that they refrained from participating in activities outside the home because their attention was constantly on their child with autism and because they felt that others did not understand their child's behaviour problems (Fox et al., 2002).

Having a child with special needs is associated with childcaring stress and less time for parents to meet their own needs (Bouma & Schweitzer, 1990; Donenberg & Baker, 1993; Escobar et al., 2005; Fombonne et al., 2001; Klassen et al., 2004; Seltzer et al., 2004). Compared with parents of typically developing children, parents of children with autism report greater family burden and are at a greater risk of experiencing physical and psychological distress (Allik et al., 2006; Bouma & Schweitzer, 1990; Fombonne et al., 2001; Seltzer et al., 2004). Further, it has been reported that the level of emotional distress in parents is positively associated with the level of challenging behaviour in the child (Allik et al., 2006; Baker et al., 2002; Fombonne et al., 2001; Klassen et al., 2004) and negatively associated with the child's ability to communicate functionally (Ello & Donovan, 2005). Financial challenges may also arise, as having a child with a developmental disability is associated with higher rates of work loss and medical costs than

experienced by unaffected families (Hecimovic & Gregory 2005; Parish et al., 2004). There is evidence that socio-economic status, as assessed using a modified Hollingshead four-factor index, is weakly associated with family stress and that there is greater family stress when the child with autism is an older adolescent or young adult (aged 15–21.9 years) rather than a younger adolescent (aged 10–14.9) (Donovan, 1988). Evidence regarding effects on siblings is mixed in that there are findings both for and against an increase in their risk for externalising and internalising adjustment problems and a decreased level of social competence (Kaminsky & Dewey, 2002). Children with developmental disabilities tend to have learning problems and poorer academic achievement than their typically developing peers (Griswold et al., 2002; Spira & Fischel, 2005). In addition, they experience difficulties in school functioning (Brereton et al., 2006), have poorer social and adaptive functioning (de Bildt et al., 2005; Liss et al., 2001), and are less independent than typically developing children (Curran et al., 2001). Independence is a particularly important issue for children with autism as they are more likely to remain dependent on their family or services for support as they age, than are children with other disabilities or medical conditions (Ballaban-Gil et al., 1996; Howlin et al., 2004; Seltzer et al., 2004). Although both autism and ADD/ADHD (attention deficit disorder/attention deficit hyperactivity disorder) are developmental neuropsychiatric disorders and are diagnosed during childhood, much research has been undertaken on QOL and parental concerns of children with ADD/ADHD (Bagwell et al., 2001; DuPaul et al., 2001; Escobar et al., 2005; Klassen et al., 2006; Spira & Fischel, 2005; Strine et al., 2006;) whereas little has been undertaken on autism.

4.6.1 Quality of Life Domains and Autism

A literature review on the influence of having a child with autism on the lives of its parents helped me to understand that several areas in a parent's life are affected. I have used the term 'domains' to refer to these areas and in the following have grouped reviewed studies according to these domains.

Emotional Domain

Emotional wellbeing of parents is the foremost domain that is affected while parenting and caring for a child with autism. Gray (2003) finds that mothers are much more likely than fathers to claim that their child's autism has severely affected their emotional wellbeing. Indeed, many mothers experience sufficient distress to require psychotherapy and/or medication. Tonmanil et al. (2004) estimates an even higher level of significantly elevated stress being experienced by two-thirds of mothers. Mothers and fathers also cope differently with emotional distress, with fathers typically suppressing their feelings, often at the cost of anger (Gray, 2003). Mothers tend to vent their feelings and have a wider range of emotional expression; feeling grief and sadness in addition to anger and crying. They rely on talking to friends and family, particularly other mothers with a child with autism, as a way of dealing with their emotions. Gray (1993) also finds mothers to be more stigmatised by their child's disorder.

Psychological Domain

Parents of children with autism appear to be at greater risk for depression, anxiety, social isolation, fatigue and frustration in obtaining accurate diagnoses and services. Individuals with autism frequently engage in behaviours that are potentially disruptive to family life such as aggression, self-injury, impulsivity, hyperactivity, temper tantrums and obsessional ritualistic behaviour. Kaminsky and Dewey (2002), Sharpley et al. (1997) and Gray (1993) emphasise that the following factors contribute to psychological stress:

- the long and frustrating process of obtaining a diagnosis
- the permanency of autism
- the lack of public understanding of autism (although this is improving)
- the lack of acceptance of autistic behaviour by society and sometimes family members
- very low levels of social support

- extremely disruptive antisocial behaviour of the child.

Vocational Domain

Gray (2003) finds bringing up a child with autism also has a significant effect on mothers' careers. Those that do manage to work are often forced to take days off work, perform below their normal level or drop back to part-time status. For some mothers, this causes resentment. Unlike children with more common disorders, autistic children in Gray's study tended to have more highly qualified parents than other children: 46% had parents with qualifications above GCSE, compared with 35% for other children. Autistic children were, however, similar to children with other types of disorder in that a relatively high proportion lived in families in which neither parent worked (30% compared with 14% of other children). The unusual combination of high educational status and low economic activity rate among the parents of autistic children likely reflects their heavy caring responsibilities (Office of National Statistics, 2005).

Financial Domain

In one study (Sharpley et al., 1997), 81.9% of parents reported that they were sometimes stretched beyond their limits, and nearly half of these felt that way monthly or even weekly. Loynes (2000) examines the financial effect of having a child with autism and finds it to be a significant burden to families. There is not only a shortfall between the costs of bringing up a child with severe disabilities and benefits received, but caring for a person with autism commonly affects the carer in their ability to work. From my professional experience a significant proportion of families of children with autism are reliant on benefits, having given up their employment because of the demands of caring for their child. However, Broach et al. (2003) show clearly that benefits designed to cover the additional costs of caring for a child with autism do not meet families' financial needs.

Domain of Marital Relationship

Parents of children with autism report greater levels of stress and depression and lower levels of marital intimacy than parents of children with typical development, or parents of children with Down syndrome (Fisman, Wolf & Noh, 1989 in Bowers et al., 2001, p. 40). Other research finds that parents of autistic children are at high risk for marital discord (De Myer, 1979; Donovan, 1988; Rodrigue et al., 1990).

Support Network Domain

In a study by Bromley et al. (2004), over 50% of parents screened positive for significant psychological distress and this was associated with low levels of family support and with bringing up a child with challenging behaviour. It is evident from this study that the lower levels of support from extended family members will add to the emotional trauma experienced by parents and will affect their coping. The lack of suitable respite care adds to this stress. Barson (1998) reported that one-third of families did not have any respite support at all, and of those that did, 28% were not satisfied with it. Obtaining respite care during school holidays is particularly difficult, with autism-specific respite services being uncommon (Loynes, 2000).

4.6.2 Remarks

These findings reveal the strained QOL experienced by parents and some of the domains of life that are adversely affected. It is evident from the literature that the QOL of parent-carers of children with autism is negatively affected. It was difficult to find studies exploring parents' perspectives of QOL. Prior to 1988, there was little research on parent-carers of children with autism (Milgram & Atzil, 1988). Few studies were conducted to explore the experiences of living with a child with autism (Koegal et al., 1992). The bulk of the research involved questionnaires, scales and self-completion reports and there is arguably an under-representation of male parents in the research. Very little research has been carried out using qualitative

approaches (Marsick & O'Neill, 1999) and many questions remain unaddressed. What meaning does a parent of a child with autism give to the term *quality of life*? What domains are important to them in describing their QOL? What indicators do they use? What are their perceptions, goals and needs that determine their QOL?

The QOL literature acknowledges that QOL has both objective and subjective dimensions (Robillard, 2000). Subjective QOL is about feeling good and being satisfied with things in general. Objective QOL is about fulfilling societal and cultural demands for material wealth, social status and physical wellbeing (Noll et al., 1998). A subjective QOL measure such as a satisfaction survey for a population may suggest a high level of QOL whereas an objective QOL measure of health or income, for example, may suggest a lower level of QOL for the same population (Robillard, 2000). This naturally raises the question of what is the best measure of QOL. Unfortunately, there is no consensus on the principles that guide the measurement of QOL (Chig-Lee et al., 2008, pp.1147–1160).

In the context of disability, there are two basic approaches for measuring QOL: a health-based approach and a person-centred approach. The first focuses on the objective parameters of physical (e.g., duration of life, cognitive abilities) and economic wellbeing. The second focuses primarily on the experiences of respondents and their subjective interpretation (Glozman, 2004).

The questions emerging in the current research explore how parents interpret their QOL experiences. The study adopts a single QOL index perspective, but focuses on describing parents' QOL experiences within a research framework. It aims to enrich the QOL literature (Velasco et al., 2000, pp.892–900) by undertaking a subjective rather than objective line of research. Corring and Cook (2007, pp. 240–244), in their literature review on QOL, identify several authors who argue that QOL has a major subjective element and can be assessed only by self-reports. Leighman (1988) emphasises that although many QOL measures use subjective self-report strategies (e.g.,

satisfaction of life domain scales, QOL scales), the indicators used in such measures are based on literature from a researcher's perspective. An approach that elicits an individual definition of a good QOL will be a more appropriate indicator of subjective QOL (Prince & Prince, 2001). Qualitative methodologies tend to focus more on subjective aspects and personal experiences, concentrate on eliciting individual's description and provide flexibility for the respondent to determine their own comparison referent to describe their QOL experience (Denzin & Lincoln, 1994). In this instance, the indicators that describe QOL should ultimately come from the respondents (as explained in a grounded theory approach). Hence, qualitative research strategies, primarily focus groups and in-depth interviews, seem appropriate for this study.

Following the above discussion, I now focus on the services provided for children with autism and their parents.

4.7 Autism and Social Care

4.7.1 History of Social Care in the United Kingdom: Autism Context

In the early years from 1943 to 1970, the medical profession considered autism to be a rare psychiatric condition with poor outcomes and the public considered it a social embarrassment (Lotter, 1966). To early clinicians and researchers, autism was linked to schizophrenia (Silverman, 2011) and, until the mid-1960s, was undifferentiated from mental retardation and/or mental illness. Institutionalisation was often recommended as the best 'solution' for the family (Bettelheim, 1967; Rutter, 1974). Bettelheim (1967), an American child psychologist, popularised his theory that children develop autism as a result of cold, uncaring mothers. He argued that traumatised, unloved children of 'refrigerator mothers' were more likely to become autistic than others (Bettelheim, 1967) and prescribed removing the child from the parents with an indefinite term of therapeutic institutionalisation (Bettelheim, 1967; Schopler & Reichler, 1971).

In this era, only a minority of children received a specific autism diagnosis. Undefined diagnostic criteria compounded its precarious acceptance within the medical and scientific community and limited its understanding and awareness. Further, many children were classed as 'hopeless', with custodial care in a mental handicap hospital or hospital for the subnormal being authorised. Wider social awareness of autism was negligible. It appears that parents during this era were isolated, with few resources or information to help them. When parents were believed to have caused their child's autism, they were scrutinised, treated, researched and stigmatised by both professionals and the public (Fraknoi & Ruttenberg, 1971; Gray, 1993).

The period between 1970 and 1990 witnessed expanded scientific and medical understanding of autism, increased public awareness and new directives in social care services. Autism began to be understood as a neurodevelopmental disability (Folstein & Rutter, 1977; Rutter, 1974) because of an impairment in the growth of the brain and nervous system. Wing (1993) introduced the concept of autism as a spectrum producing a wide range of cognitive and neurologic impairments, expanding the recognition and inclusion criteria for diagnosis. Community care policies, notably the de-institutionalisation or long-stay hospital closure programmes of the mid-1970s, prompted radical transformations in societal views of developmental disorders (Eyal, 2013), moving care and support decisions away from healthcare professionals to local authorities. Development of community care and long-stay hospital closures, combined with the shift to commercial social care services, placed social workers in new roles as gatekeepers of local authority funding and as care managers with responsibilities for assessment, care planning and review (Burnham, 2012).

Understanding the aetiology of autism is critical for developing effective interventions; yet, despite extensive research, the specific cause and risk factors of autism remain elusive. Autism is now defined as a complex neurodevelopmental disorder with genetic and environmental causal factors (Currenti, 2010). It is no longer considered a rare condition, with diagnostic

prevalence rates having increased dramatically (Fombonne, 2003; King & Bearman, 2009). Greater medical awareness, changes in diagnostic criteria and more sensitive screening may have contributed to this increase.

Professional social support emerged in 1967 when a Child Guidance Special Interest Group (CGSIG) was established by psychiatric social workers to meet the needs of 'disturbed' children (Younghusband, 1978). Its members included social workers who worked with families of these 'disturbed' children and offered advice and information about community resources and supportive parent organisations (Younghusband, 1978). The *Local Authority Social Services Act 1970* established a single social services department in each local authority, emphasising the need for a coordinated and comprehensive approach to supporting families, detecting need and encouraging help-seeking (Department of Health, 1970).

4.8 Local Authority Services for Children with Autism and Their Families

It may be a reasonable expectation that research into children's services would rest on a clear understanding of what a service should be and how to measure it. However, it is surprisingly difficult to identify in the literature explicit definitions of 'service'. We seem to flounder between the assumption that everyone knows what is meant and a worry that delving any deeper will unearth a multitude of complexities. The diverse ways in which services are measured reflects this ambiguity. This is problematic for several reasons. First, we need to know how services relate to the type and severity of needs and, in particular, if provision is adequate, appropriately matched and equitable (Ford, 2008). We also need to understand how individuals interact with and move through services, as services can only be useful if children and families use them (Zwaanswijk et al., 2003). The usage of services is a prelude to identifying predictors of service use, which in turn is valuable information for policy makers and managers seeking to maximise service uptake (Spielberger & Lyons, 2009).

It is critical to understand the role of child or family's *place* in a service and this could begin by ascertaining whether they are receiving a service. The interaction of a child or family with a service is commonly referred to as service 'use' or 'receipt', or having a 'contact' with a service. These terminologies are used interchangeably, alongside 'getting help' or 'providing care'. Different terms indicate varying degrees of passivity or autonomy on the part of the child or family and some arguably stigmatise or exclude (Vojak, 2009). It is often the case that the line between being in the service provider system as a 'case' and actually receiving assistance or help from the provider is blurred. For example, a family can be described as engaging or involved with social services when their case files indicate very little actual engagement or activity. There is usually a period between when the individual first has contact with the service (entry in to the service) and their exit from the service. This period could be described as their journey through the service and may be further elaborated as a temporal 'chain' or 'sequence' of services used, or the 'mix' of services received. Thus, a child may be dealt with initially by a health or education professional, but passed on to a social worker. A more fine-tuned conceptualisation differentiates between the means by which contact occurs. A case may be opened following referral from a third party (an agency or individual) or following self-referral (the individual or family who need the service refer themselves). Goldberg and Huxley (1980) explain that a series of filters operate between, say, the community and a primary care professional, and then between that professional and the service provider to whom they are referred. An individual's or family's place in the service is contextualised by their relationship to the service provider or professional. This is about power and the degree of compulsion with which services are used: service users using a service are usually familiar with a single event or string or process when engaging in services. However, service users also exhibit their own service-using behaviour. There is a difference between a parent volunteering for a course to help them parent an adolescent with conduct problems and the same adolescent being incarcerated for antisocial behaviour. The language

used can portray the relationship, but this is unreliable. Terms such as 'consumer' or 'user' suggest choice and influence over the service but are used interchangeably with the more passive 'recipient' (McLaughlin, 2009).

As autism began to be understood as a neurodevelopmental disorder, parental stress associated with raising a child with autism was acknowledged, with social services assessment and entitlements enacted under the *National Health System and Community Care (Scotland) Act 1990*, the *Carers (Recognition and Services) Act 1995* and, more recently, the *Care Act 2014*. Given the current research is based in Scotland, the section that follows provides a brief outline of service provision for children with disabilities and their families in Scotland.

The Scottish welfare system comprises support services provided by local authorities, the private sector and voluntary organisations for children with disabilities and their parents. Section 12 of the *Social Work (Scotland) Act 1968* empowers local authorities to provide advice, guidance and assistance as appropriate to promote social welfare. This means that local authorities have general powers under this Act to provide help and support to children with disabilities and their families in Scotland.

There has been a growing recognition of the contribution made by carers to UK society in recent years (Department of Health, 1999). Carers are referred to as those who look after their relatives or friends who are fragile, vulnerable or disabled (Department of Health, 1999). Around 60% of carers in UK are caring for people with disability and the act of caring seem to form an important part of the fabric and character of Britain.

In response to the ongoing commitment of the UK Government to support carers, a national strategy for carers titled *Caring for Carers* was published in 1999. It acknowledged the fact that the needs of carers are only being met patchily. Helping carers was seen as one of the best ways to help the people for whom they are caring (Department of Health, 1999).

The Scottish Executive published the strategy for carers in Scotland in 1999 and this policy document identified five major priorities for carers: the promotion of new and flexible services for carers including respite care at a local level; the introduction of national standards for such services; the need for monitoring by the Scottish Executive of the services provided by health and social services; the introduction of legislation to allow carers' needs to be met more directly; and the provision of better and more targeted information for carers at a national level (Scottish Executive, 1999).

The *Social Work (Scotland) Act 1968* empowered local authorities in Scotland to deliver services to carers to achieve the priorities set out in the policy document. However, in Scotland, parents of a child with disability are not covered under the *Carers (Recognition and Services) Act 1995*. Nonetheless, parents who care for their own disabled child under 18 years of age have a right to assessment (if requested) as part of the overall assessment of the needs of the disabled child under the *Children (Scotland) Act 1995*. The current research intends to specifically focus on the services provided directly/in partnership/commissioned/referred as referrals by the social work departments of local authorities for children with disabilities (autism) and their families (parents). One of the major reasons for focusing on the services provided/commissioned by social work departments of local authorities is the statutory responsibility with which they are bestowed for the protection and promotion of the welfare and wellbeing of families of children with disability (*Children (Scotland) Act, 1995*). It is important to note at this juncture that data collection for this research was completed in 2011, prior to the implementation of SDS legislation, however the local authorities did have the option to implement direct payments.

4.9 Social Work Services

Children with more severe levels of disability allied with autistic features, and who were pre-pubertal, have an increased risk of displaying challenging behaviours (Chadwick et al., 2008). Most children displaying challenging

behaviours live with family carers. The deleterious effect of this on parental health, stress and family functioning is well documented (Hastings, 2002).

Lancaster (2012) conducted a study of social work services for disabled children and their families in Scotland. She identifies that the local authorities of Scotland place responsibility on their education and social work departments to provide the majority of services for disabled children and their families. Within social work services, most (19 of the 23) local authorities have a team dedicated to dealing specifically with disabled children and young people who carry out assessments to identify the needs of a child with disability and their families. Lancaster highlights that there may be differing practices across local authorities relating to children with ASDs, with some local authorities not covering all conditions on the spectrum. Practical assistance in the home (e.g., with personal care of a child), equipment and adaptations, short-break respite, residential respite and day care (e.g., child minding, family centres and out-of-school care) were the only services reported as being provided by all 23 local authorities.

A few researchers, including McConkey et al. (2013), study the usefulness of specialist respite breaks in residential units for parents of children who are severely challenging. A closer examination of the sample in that study indicates that it includes parents of children with all types of disability (mostly learning disabilities with associated diagnosis of autism). The sample does not clearly explain gender differences in the parents who participated in the study or outline the number of parents whose child had autism as the primary diagnosis. The research finds that the parents' experiences of accessing respite in specialist residential units highlight the complexities underlying the provision of services.

This initial literature review was completed prior to the data collection. A further literature review update on services for children with autism and families including services streamlined by social work was completed post data collection which is documented in the latter part of this thesis (see chapter 10).

The initial literature review that specifically illustrates the QOL experiences of parent-carers of children with autism after receiving services from the social work department of local authorities was relatively unsuccessful. It was difficult to identify studies that primarily explore parents' experiences of children with autism in relation to services received from social work departments. I used the electronic journal search provided by the University of Edinburgh library to search for articles related to this topic because of increasing accessibility to a wide range of literature online. I used the keyword term 'social work services and autism' to search for the articles online. The University of Edinburgh online electronic search facility subscribes to 212 journals in the category Social Welfare and Social Work. All these journals are accessible through their publishers' websites. I searched 11 of the major publisher websites—SwetsWise, Informa World, Wiley Interscience, Oxford Journals, Springer Link, Sage Journals, JSTOR, Science Direct, ACM Digital Library, Ingenta Connect and Cambridge Journals—that make all journals available dating from 1969 to 2010. A search in SwetsWise generated eight articles, but none specifically related to autism. A similar search in Informa World generated six articles, of which four related to respite breaks but contained little or no specific information of relevance. Wiley Interscience generated 11 search results, all related to medical literature. The same search was repeated for the other publisher websites with similarly low success. This suggests there is scope for research to explore QOL experiences of parents of children with autism in relation to the services provided by the social work departments of local authorities as proposed in the current study.

4.10 Argument for this Research Study

It is acknowledged that the incidence of autism is on the rise in Scotland and autism is identified as a priority for the Scottish Government. However, there is a gap in research related to autism in the Scottish context.

Autism is a lifelong condition that affects day-to-day functioning. Autism also affects the lives of the parents of children with autism, who play a key role in

caring for them. A review of parents' experiences of children with disability indicates that there is an under-representation of studies focusing on fathers. It is also noted that studies focusing on children with disabilities encompass a wide range of disabilities and it is uncommon for children with disability to have coexisting conditions. Given the heterogeneity of ASD, there is scope for a study that focuses specifically on parents of children with autism.

Understanding the QOL experiences of parents in the context of Scottish social work services would be helpful for a number of reasons. First, from a political perspective, it will further inform the Scottish Government about the specific implications of autism for its citizens (parents), which could inform policy and strategic developments to optimise the wellbeing of its citizens. Such understanding may also be beneficial for the micro-level service delivery planning initiated by Scottish local authorities to cater to the needs of children with autism and their families. From a professional perspective, practitioners such as social workers and support workers who have direct engagement with children with autism and their families could draw upon the QOL experiences of parents to reflect on their practices and identify scope for further refinement or development in their practices and assessments. For the parents of children with autism, it may be helpful to realise that their experiences are acknowledged and valued and that an attempt has been made to capture their individualistic perspectives.

It is understood from the literature review that QOL can be measured using objective or subjective approaches. Subjective approaches focus on understanding individual perceptions as underlies the current study; such studies usually align more with a qualitative research paradigm. Although a number of scales are available to understand subjective QOL experiences, it is acknowledged that there is insufficient explanation of how the indicators of these scales have been developed. Further, it is understood that the indicators vary depending on the context of the person.

I argue that parents of children with autism are best placed to explain how they make sense of their QOL experience, in a study that gives them the

flexibility to explain what they see as important in formulating their QOL experience. Hence, this study adopts an unconventional approach to explore parents' QOL experiences, without the utilisation of standard scales. The chapter on research methodology provides further details of this approach.

Chapter 5: Research Design

5.1 Introduction

This chapter outlines the study's research design. A research design is a systematic plan to study a research problem. Developing an appropriate research design is one of the important challenges faced by a PhD student. Phillips (1976) refers to this component as the *Magna Carta* of research. The research design is an integral part of a study as it spells out in detail the theoretical (research questions, ontological and epistemological positions, and ethical considerations) and practical frameworks (data collection methods and data analysis process) that underpin the study.

Beginning with the research aims and objectives, this chapter proceeds to discuss the ontological and epistemological positions, the grounded theory methodology (GTM), a perspective on evaluating the study and ethical considerations. In short, the aim of this chapter is to elaborate in detail on the theoretical framework encapsulating the research design.

5.2 The Research Problem

When I began my PhD journey seven years ago, I was a recently qualified social worker with a keen interest in academia. I was fascinated by the world of research, or should I say 'naively fascinated'. Am I still fascinated? Maybe I should blog about it another time.

During my social work training in India, I had the opportunity to work with children with autism and their parents, and that experience made an imprint in my head and heart like no other. A spin of life events brought me to Scotland where I began to work closely with children and young people with complex disabilities (including autism) and their families. The world of autism continued to fascinate me. It did not take me long to realise that autism is a relatively new cohort in the social care service (technically known as social work or social welfare) in Scotland. Therefore, when it came to writing my

research proposal, I began to do some serious reading (more familiarly known as a literature review in the research world), which revealed a dearth of research exploring parents' experiences of living with a child with autism (Koegal et al., 1992).

Being a practising social worker in Scotland at the time (I have now relocated to Australia), my inquisitiveness extended to understanding the parents' experiences with the Scottish social work system. Underpinning the ethos and values of any social work practice is the ideology to engage with people to enhance their wellbeing (International Federation of Social Workers, 2013); that is, to help improve their QOL experience. To understand this further, I was keen to hear the perspectives of social workers and operational managers as the office bearers of help, and parents as the recipients of that help. This personal and professional curiosity was technically reaffirmed by the identification of gaps in the literature regarding the same (refer chapter 4 literature review for details). After reams of drafts and redrafts (the joys of being a novice researcher), the research aim and research questions were finalised as below.

5.3 Research Aim

5.3.1 Aim of the Study

The overall aim of this study is to explore the QOL experiences of parents of children with autism in Scotland. The study aims to understand how parents interpret their QOL experiences. It does not adopt a single QOL index perspective, but focuses on describing parents' QOL experiences within a broader research framework. It aims to enrich the existing QOL research literature (Velasco et al., 2000, pp. 892–900). Corring and Cook (2007, pp. 240–244), in their literature review on QOL, identify several authors who argue that QOL has a major subjective element and can be assessed only by self-reports. An approach that elicits an individual definition of a good QOL will be a more appropriate indicator of subjective QOL (Prince & Prince, 2001).

5.3.2 Specific Objectives of the Study

Objective 1: To explore how parents make sense of their child's autism and its influence on their QOL.

Objective 2: To explore whether male and female parents have a differing view about QOL and understanding of autism.

Objective 3: To describe parents' experiences of accessing social work services from local authorities and its influence on their QOL experience.

5.3.3 Research Questions

The research questions addressed in this study are:

What does the term *quality of life* mean to parents of children with autism?

What are the parents' experiences of engaging with local authority social work for potential services?

To what extent have services offered from social work assisted parents?

Is there a scope for changes in current social work service provision in the autism context?

5.4 Philosophical Perspective: Ontology and Epistemology

5.4.1 Ontology

The research aims and questions discussed in the previous section are expected to generate data that may inform social work policy and practice related to children with autism and their parents. This raises two important questions: What counts as valid knowledge? How could this be generated? Ontology is the philosophy of what we believe to exist (philosophy of being) and epistemology attempts to explain how we know what we believe to exist (philosophy of knowledge) (Smith, 1998).

At one end of the ontological spectrum is the view that the nature of being, existence, reality or truth is out there, summarised as the 'realist' perspective. The other end of the spectrum assumes that reality is constructed by social actors and is more commonly known as the 'relativist' perspective (Currie, 2013). This study aims to explore parents' perspectives of their QOL experiences. In addition to speaking to parents, I spoke with social workers and operational managers to understand in greater detail the parents' experiences in the context of social work services. I argue that the perspectives of parents and social workers are subjective and they use language as the basic construct to express what they experience at an empirical level. This would converge with the 'relativist' stance as beautifully described by Bryman (2004, p. 17); that social actors construct social reality and that this reality is in a state of constant revision.

5.4.2 Epistemology

The idea of what is essentially considered knowledge links closely to how knowledge could or should be generated; that is, to shape the epistemological position. In general, these fall along a continuum with positivist or objectivist approaches at one end and interpretive or subjectivist approaches at the other (Raddon, 2013). Presented below is are the various epistemological perspectives that I came across in the literature.

In objectivist perspective, knowledge is underpinned by a realist ontology in which facts and the knowledge are deduced using a scientific method (Yates, 2004). Knowledge or the theory generated must undergo rigorous testing to be proved or disproved (Reid, 1994). As explored in the chapter 4 literature review, research studies rooted in objectivist ontology are conducted using questionnaires and surveys; however, the criticism remains that the tools used are developed from literature derived from researchers' perspectives, indicating that a researcher has an active role in knowledge generation rather than being a passive outsider.

At the other end of the continuum is the subjectivist or interpretive approach. It holds the view that the subject matter of social sciences (people and institutions) is fundamentally different from natural sciences. As Schutz (1969) summarises, the world of nature as explored by natural scientists does not mean anything to the atoms, molecules and electrons. However, social reality has a specific meaning and relevance structure for the beings living, acting and thinking within it. The data generated are perhaps more qualitative in nature. Raddon (2013) argues that people are people (relativist ontology) in this paradigm, and knowledge is a product of its place and time, mediated by those who construct it (Dey, 1993).

They acknowledge that all research questions carry implicit assumptions and biases, suggesting that knowledge can never be purified—it is always produced by someone, somewhere, at some time, for some purpose—and that this subjectivity should be acknowledged (Shaw & Gould, 2001). Other epistemological orientations that can generally be argued as the offshoots of the interpretative or subjective paradigm include pragmatism, hermeneutic-phenomenological, symbolic interactionism, post-modernism and constructivism (Gibbs, 2001).

The questions addressed in this research explore how parents make sense of their QOL experiences while living with a child with autism and engaging with social work. Attempts to answer this question will be unsuccessful if the researcher does not understand the context of each individual parent and their interactions with the child and social work services. In other words, in this study, the QOL experiences of parents (individuals) are understood through their interpretations (symbolic meanings) of living with a child with autism and any help they receive from social work (environment). Hence, it can be argued that this study is more aligned to the epistemological stance of symbolic interactionism.

So what is symbolic interactionism? Schutz (1969) explains that individuals are continually interpreting the symbolic meanings of their environment and acting on them. George Mead is considered one of the pioneers of symbolic

interactionism; however, it was his student Herbert Blumer that coined the term symbolic interaction 40 years after Mead's death in 1969. This perspective is based on the following three tenets Blumer, 1969, p. 2):

- 'Human beings act toward things on the basis of the meanings that the things have for them.
- The meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows.
- These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things that he encounters.'

This implies that the person is continually interacting with the environment and that significant symbols (shared meanings) emerge in this growing and changing process (Robbins et al., 2006, p. 296). Annells (1996) argues that language is a symbolic system commonly used by people to interpret shared meanings. The individual can use language to interpret meanings through social interactions, to take action and to evaluate consequences.

The discussion that follows aims to justify that an inductive line of knowledge generation was a better approach for this research study. The research questions posed aim to understand how parents describe their QOL experiences. A considered choice is made to be sensitive to the domains and indicators flagged by the respondents, rather than those listed in QOL measurement tools. Understanding parents' interpretation of living with a child with autism and their experience of engaging with social work services was central to this study. These processes and interpretations set the scene for the researcher to understand the person in the environment.

A criticism of studies that adopt existing theories (e.g., systems theory) or predetermined data gathering tools (QOL scales)—as in the deductive approach to social science research—is that such frameworks might limit the terms of the inquiry and data generated; there is also the possibility of ignoring or missing alternative explanations (Blaikie, 2000). Hence, the

current research proceeds inductively, while recognising the contribution of theory and acknowledging differing perspectives.

5.5 Qualitative Research

Creswell (2003) explains that there are three main types of research: quantitative research, qualitative research and mixed methods research. Quantitative research is used mostly in the following instances: when the research problem is aimed to identify the factors that produced a particular outcome; test a hypothesis or predict an outcome; or measure the effectiveness of an intervention. Qualitative research is undertaken mainly to understand the concept in a natural setting, or when little is known about the topic. A mixed methods approach is adopted when the researcher seeks both generalisation and detailed understanding of the phenomenon (Creswell, 2003).

This study is qualitative in nature for several reasons. First, the research questions have a more qualitative nuance. The study aims to find meanings and answers through the eyes of parents, who are seen as the experts. The questions allow discursive descriptions and exploration of the parents' meaning and interpretation from their perspective. One of the features of qualitative research is that it explores a research problem from the respondents' perspective (Blaike, 2000, p. 232; Marshall, 1996, p. 522), which is clearly the case in this study. This study gives value to the experiential knowing and insights gained through personal involvement with reality (Pickering, 1980). Living with a child with autism is a personal experience, a reality that is unique to them. Eliciting a snapshot of their experience of living with autism and their experience with social work is necessary to describe their QOL experience.

Second, a qualitative design is 'multi method in focus, involving an interpretive, naturalistic approach to its subject matter' (Denzin & Lincoln, 1994, p. 2). A qualitative platform requires this study to adopt data collection and analysis methods that can provide richer and more elaborative answers

to the questions posed to respondents. Qualitative research gives respondents the flexibility to describe and share their interpretations and experiences, which can provide valuable insights. It offers an array of data collection tools such as focus groups and interviews that facilitate the researcher in gathering descriptive and rich data from research subjects (Ewings et al., 2007). It enables the researcher to present the research data in a descriptive fashion based on interpretative understanding (Schutz , 1962).

Finally, qualitative research better encompasses the epistemological position of symbolic interactionism, reinforcing the argument that this study attempts to give importance to the subjective interpretations of parents living with a child with autism. It generates a worm's eye view of the QOL experiences of parents of children with autism through interpretations and descriptions (Blaikie, 2000).

The following section discusses the choice of grounded theory as the most appropriate methodology to understand the research problem in this study.

5.6 Research Methodology: Grounded Theory

Crotty (2003, p. 3) defines methodology as 'the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes'. Broadly speaking, qualitative research has an array of five methodological choices: ethnography; grounded theory; case study; phenomenology or interpretive phenomenological analysis (IPA); and narrative research. Ethnographic studies examine the behaviours and rituals of an intact cultural group over a long period in their natural setting, primarily using observational data. Case studies undertake in-depth analysis of a programme, event, process or individual using multiple methods including documents, archived records, observations and interviews. Phenomenological research employs lengthy interviews with limited participants to understand their experiences of a phenomenon, and narrative research shines a spotlight on the lives of

individuals studied through collection of life stories using interviews (Hartley & Muhit, 2003, p. 105). The goal of phenomenology or IPA is to focus on the lived experience of the phenomenon of interest, and in grounded theory the concern is to develop an explanatory theory of basic social processes. As Goulding (2005, p. 304) concludes, grounded theory is 'a methodology particularly suited to situations that have a symbolic and, or, an interactional element to them', making it well suited to this thesis.

As the two key drivers of this research are to explore the perspectives of parents and to contribute to social work practice, it was concluded that IPA and grounded theory are the two most relevant approaches. The following discussion compares these two methodologies (Goulding, 2005; Starks & Brown Trinidad, 2007), to crystallise understanding of the differences between them.

IPA is designed to discover phenomena and unearth previously unnoticed or overlooked issues, as it explores the experience and meaning of phenomena. IPA, therefore, reveals meanings that appear 'hidden' or identifies the effect of a phenomenon, rather than making inferences. At the same time, this approach provides rich descriptions that aid understanding. The result of uncovering this knowledge is that a researcher may better understand the possibilities embedded in the experience of phenomena. The goal of IPA is to develop an understanding of a phenomenon through the specific human experience of the phenomenon, to better understand the experience of being in that 'life-world'. It serves to understand a person's experiences rather than to provide a causal explanation for those experiences. The process of phenomenological research, therefore, does not 'break down' the experience being studied. Instead, it provides descriptions that are rich and full and interpretations that exactly describe what it means to be a person in their particular world. The phenomenological researcher is committed to understanding the experience of the phenomenon as a whole, rather than parts of that experience. IPA, therefore, is mostly used to develop 'pathic' understanding.

The literature often uses terms like IPA and thematic analysis interchangeably. However, the main difference between thematic analysis and IPA or grounded theory is that thematic analysis is a method, whereas grounded theory and IPA are methodologies. A thematic analysis, however, is differentiated from a grounded theory in that it aims to summarise data into themes that are then explained, rather than necessarily developing a novel theory to describe the findings (Ryan & Bernard, 2000). Thematic analysis is by no means uniform and is often only partially explained. The processes of coding undertaken are rarely specifically described.

Grounded theory is a widely used qualitative methodology, particularly as a means to inductively separate issues of importance by creating meaning about those issues through the analysis and modelling of theory. Grounded theory is associated by many with the notion of symbolic interactionism—a term coined by Blumer in 1937. This process aligns an interactionist approach alongside naturalistic inquiry to develop theory. This is where individuals are known to share culturally oriented understandings of their world; where understandings are shaped by similar beliefs, values and attitudes and determine how individuals behave according to how they interpret the world around them. People are seen as being both ‘self-aware’ and ‘aware of others’ and, therefore, can adapt their social interactions and situational behaviour to shape meaning and society. In this sense, the focus lies with the symbolic meanings that are uncovered by people’s interactions, actions and resulting consequences.

It is my understanding that there is strong possibility that the results generated by a grounded theory approach, IPA or thematic analysis will be rather similar despite the different analytical procedures used by the three methods. However, it is important to settle on one method/methodology and I chose grounded theory; the rationale for this is multifaceted, as is now discussed.

Given that the purpose of this research is to make sense of the interpretations (symbolic meanings of the interactions) between a parent and

their child with autism and with social work services, with a view to understanding their QOLs (consequences), grounded theory is the preferred methodology.

Originally conceptualised by Barney Glaser, a quantitative researcher and Anslem Strauss, a qualitative researcher, in the mid-1960s, grounded theory is of particular value to social work research because both have common roots in symbolic interactionism. It is appropriate to recall here that the theoretical foundations of symbolic interactionism underpin this social work study looking examining the QOL experiences of parents of children with autism in Scotland. In their pioneering book *The Discovery of Grounded Theory*, Glaser and Strauss (1967) articulate the process of developing a theory from qualitative data by explaining the strategies they adopt in a collaborative research project on dying (Glaser & Strauss, 1968).

Morse et al. (2009, p. 18) writes, 'Grounded theory is a way of thinking about data—processes of conceptualization—of theorizing from data, so that the end result is a theory that the scientist produces from data collected by interviewing and observing everyday life'. This focus on the development of middle-range theory is the primary way that grounded theory differs from other qualitative methods (Corbin & Strauss, 2008; Hood, 2007). This aligns closely with my intent to develop a theory on the QOL experiences of parents of children with autism that is understandable to practitioners in the field and will apply in real-life settings. It therefore serves an academic and professional purpose. Figure 1 presents the key concepts underlying grounded theory.

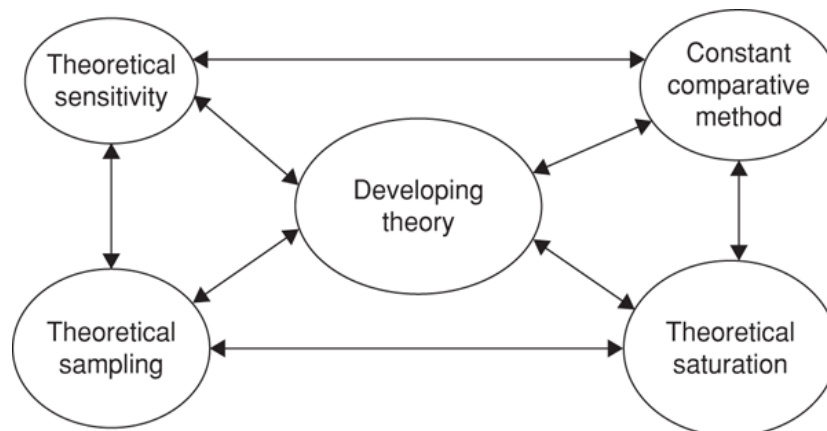


Figure 1: The key concepts of grounded theory (adopted from Oktay, 2012)

Theoretical sensitivity is the ability of the researcher to be analytical and describe the problem under study in theoretical terms. Familiarity with sociological theories and concepts, personal and professional experience and temperament form its basis.

Constant comparison is the basic method used in grounded theory to generate theory from qualitative data that are gathered. By comparing the interviews of each parent and professional who participated in a study, the researcher develops concepts. The drill of constant comparison makes similarities and differences among cases apparent. Repeating this process facilitates development of conceptual categories based on data (Glaser & Strauss, 1967, p. 46). A discussion on the generation of codes and categories is provided later in this chapter.

Theoretical sampling in grounded theory is driven by the developing theory. The sample used to generate the theory is not representative in the same way as it is in a quantitative study. In quantitative research, the characteristics of the focal sample are often demographic. In a grounded theory study, however, the aim is a sample that allows thorough exploration of the relevant concept (Glaser & Strauss, 1967, p. 46). Given that this study had to be completed within the time frame of the PhD course, theoretical sampling in its purist sense was not logistically possible. Hence, I use

purposive sampling, which is very closely linked to theoretical sampling. However, this deviation from the purist approach is acknowledged as a limitation of this study as there is a possibility to guide the theory that is emerging, as opposed to it emerging freely. The implications of using purposive sampling in a grounded theory approach are discussed further later in this chapter.

Theoretical saturation means that 'no additional data are being found whereby the sociologist can develop properties of the category' (Glaser & Strauss, 1967, p. 61). Glaser and Strauss indicate that not all categories and concepts need to be developed to a point of saturation, but saturation is essential for what they call 'core categories' (1967). A discussion on how theoretical saturation was achieved in this study and its associated challenges is presented later this chapter.

The next section discusses the different schools of grounded theory.

5.6.1 Schools of Grounded Theory

As one examines the literature on grounded theory, it quickly becomes apparent that there was a divergence in the original authors' views and a bifurcation of the enveloped theory; Glaser worked alone while Strauss presented his treatise with his colleague Juliet Corbin (Glaser, 1992; Strauss & Corbin, 1990). This led to the creation of two schools of grounded theory; the Glaserian version based on the original work and the Straussian version based on refinements made to the original version (Benoliel, 1996; Charmaz, 2006; Heath & Cowley, 2003; McCallin, 2003). The differences between them can influence the direction and execution of a research study. Table 2 summarises the differences between the two schools.

Following the completion of an in-depth review of the literature on grounded theory, it was necessary to make the decision regarding which school would be more appropriate for this research study. The PhD framework expects me to argue a case for my research proposal, which requires considerable

literature analysis. The Straussian school has flexibility built in to formulate a general understanding of the problem under study. Being a novice researcher, it was more appealing to have access to prescriptive tools and procedures for data collection (semi-structured interviews) and analysis (rigorous coding techniques); again this is made more explicit in the Straussian than the Glaserian version. This school acknowledges the active role of the researcher in interpreting the theory and supports the inductive course of knowledge generation as discussed in previous sections. Tackling issues of rigour and credibility is another important component of any PhD thesis. The Straussian school argues that the credibility of the theory is linked to the rigour of the method, which allows the preparation for each stage of the study. Now that I have explained my choice of Straussian grounded theory approach, I move on to discuss data collection tools.

Table 2: Differences between the Glaserian and Straussian schools of grounded theory (adapted from Jones & Alony, 2011)

Glaserian	Straussian
Beginning with general wonderment (an empty mind)	Having a general idea of where to begin
Emerging theory, with neutral questions	Forcing the theory, with structured questions
Development of a conceptual theory	Conceptual description (description of situations)
Theoretical sensitivity (the ability to perceive variables and relationships) comes from immersion in the data	Theoretical sensitivity comes from methods and tools
The theory is grounded in the data	The theory is interpreted by an observer
The credibility of the theory, or verification, is derived from its grounding in the data	The credibility of the theory comes from the rigour of the method
The researcher is passive, exhibiting disciplined restraint	The researcher is active
Data reveal the theory	Data are structured to reveal the theory
Coding is less rigorous; a constant comparison of incident to incident,	Coding is more rigorous and defined by technique. The nature of making

with neutral questions and categories and properties evolving. Care is taken not to 'over-conceptualise' and identify key points	comparisons varies with the coding technique. Labels are carefully crafted at the time. Codes are derived from 'microanalysis which consists of analysis data word-by-word'
Two coding phases or types: simple (fracture the data then conceptually group it) and substantive (open or selective, to produce categories and properties)	Three types of coding: open (identifying, naming, categorising and describing phenomena), axial (the process of relating codes to each other) and selective (choosing a core category and relating other categories to that)

5.6.2 Limitations of Grounded Theory

The GTM has advantages but has also been criticised. As experienced in the course of this research, the GTM is highly complex and time consuming because of the tedious coding process and memo writing that forms part of the analysis (Bartlett & Payne, in McKenzie et al., 1997). Other limitations with the use of GTM to explain, predict a phenomenon or build a theory is that it is a highly subjective process that relies heavily on the researcher's abilities. This study follows the guidance of Strauss and Corbin (1998) to gather and analyse the interview data. Many studies make use of the term grounded theory inappropriately. Stern (in Morse, 1994) criticises some researchers for mixing methods such as ethnography and phenomenology and then using the label grounded theory to explain the analysis of their research findings.

5.7 Selecting the Study Local Authorities

Scotland is divided into 32 local authorities for administrative purposes; the health needs of the residents of these local authorities are catered to by 14 NHS boards (www.directgov.uk; www.show.scot.nhs.uk). Following an analysis of NHS board area statistical information relating to children and young people with ASD, the Social Work Statistics Branch of the Scottish Government (2004) suggests that over 3,400 children and young people have ASD. The report (2004) further explains that 52% of children fall into the

age group of 5–10 years and 26% are 11–16 years. This implies that a total of 78% of the children diagnosed with ASD are within the age group of 5–16 years. NHS board 1 (84.9%) and NHS board 2 (74.3%) have the highest percentages of ASD cases in this age group. Three local authorities in these NHS areas—study local authority 1 (population 468,070), study local authority 2 (population 581,940) and study local authority 3 (population 167,770)—were shortlisted for the current study because they represent a range of population sizes (the former two being the largest and the latter being the smallest in Scotland) and social demography, and provide services in different ways (General Register of Scotland, 2007; Scottish Government, 2003). The diverse social demography of these three local authorities was seen as an advantage with respect to identifying respondents from ethnic minority groups. It is also supportive to the research that these local authorities have active parent groups organised by local autism societies, which was considered an added advantage for recruiting participants.

All three study local authorities had a specific social work team catering to child(ren) with disabilities and their families. Two study local authorities each had one team for children with disabilities and the other had three disability teams. Study local authority 1 was divided into four neighbourhoods, each of which had one or two area offices for children and families' social work. Work is underway in this local authority for the formation of a central practice team for children with disabilities. In contrast to study local authority 1, study local authority 2 appears to have adopted a more satellite approach to organise children and families' social work service. This local authority was split into three main geographical localities, each of which had a dedicated disability team for children and families affected by disability. Each of the three localities in this study local authority also had a carers' centre, unlike the other two study local authorities. Study local authority 3 appears to have a centralised team for children with disabilities and their families.

5.8 Selection of Participants

5.8.1 The Sampling Process

The respondents in this study were the parents (father and/or mother) of a child(ren) with autism. For the purpose of this study, the operational definition of a parent was the child's biological father or mother. Participants had to have at least one child with a primary diagnosis of autism and the child must fall within the age group of 5–18 years. These criteria for selection were based on previous research showing that the majority of children with autism live with their biological parents (Stiell et al., 2006), coupled with my personal interest in examining the experiences of biological parents of children with autism. Father and mother from the same family unit were considered for the study as the QOL experience might vary according to gender. Speaking to other stakeholders—including social workers and operational managers across the three study local authorities who were involved in delivering social work services to children with autism and their families—was also considered necessary to gain a deeper understanding of the QOL experiences of parents in the context of social work services.

GTM proposes the use of theoretical sampling that is guided by emerging theory and is concerned with where to sample next and for what theoretical purpose (Strauss & Corbin, 1990). However, Dey (1993) cautions researchers not to confuse an 'open mind with an empty head' (p. 176). There is an unavoidable need to begin somewhere. For this study, I negotiated access with three local authorities and three voluntary organisations to recruit parents, social workers and operational managers. It was an explicit requirement for access that I stipulate the anticipated number of participants. The parent participants were recruited with the assistance of the three study local authorities, two autism societies/carers' centres. The social workers and operational managers were identified from the children with disability teams of the respective study local authorities. Recruiting parents (fathers and mothers) was far more challenging than recruiting social

workers and operational managers. Coyne (1997) explains 'the researcher must have some idea of where to sample, not necessarily what to sample for, or where it will lead' (p. 625). Use of theoretical sampling in this process is substantiated by purposeful selection of an initial starting point. Hood (2007) suggests 'all theoretical sampling is purposeful, but not all purposeful sampling is theoretical' (p. 158).

Studies conducted using grounded theories suggest 30 as an average sample size that can be used as a guide for the grounded theory approach (Sandelowski, 2000). This was the basis of projections for participant numbers provided to the organisations that granted access.

Glaser (1978) also writes about ensuring variation in a sample to enhance theoretical variation. To operationalise this, the parents, social workers and operational managers recruited in the study varied in their age, experience, ethnicity and so on. An explicit search for data to perform a negative case analysis was made by recruiting two groups of parent respondents (Group A and Group B) for the interview. The child(ren) of the parents in Group A had social work services from the study local authority. Group A constituted the majority of parent respondents in the study; therefore, naturally it is the larger of the two groups. Group B was a smaller group of parent respondents who did not engage with social work. Parents in Group A were recruited through the social work departments or parent groups based in the three study local authorities. The parent respondents in Group B were recruited through organisations providing support for people with autism and carers' centres based within the geographical boundaries of the three study local authorities. Social workers and operational managers were recruited from all three study local authorities, again to ensure richness and variation in the sample.

5.8.2 The Recruitment Process

Once the three study local authorities were finalised and the research proposal was approved to proceed to the data collection stage, the researcher completed written applications to the three study local authorities

seeking research access. The researcher also submitted research access requests to the two voluntary organisations operating within the geographical boundaries of the local authorities. One organisation responded within a matter of weeks and the other in a few days, granting access. For the remaining three, several months and intense follow up via phone calls and emails was required to eventually confirm access.

To ensure that an adequate number of parents and professionals was recruited, I held informal meetings and discussions with the key people in the study local authorities, satellite centres, autism societies and parent groups to maximise the potential to recruit the anticipated sample. The operational definition of parents in this study was made clear to the professionals and included any male or female biological parent of a child between 5 and 18 years with an autism diagnosis. The social workers and the coordinators of the local authorities and voluntary organisations were the 'gatekeepers' of the parent sample in this research. To minimise over-representation in the sample of participants who regularly volunteer for research studies (more commonly known in the literature as the 'usual suspects'), invitations were sent to all parents known to the local authority or voluntary organisation who had a child or children diagnosed with autism. This was necessary to ensure that an equal opportunity was offered to all parents who met the criteria to participate in the research process. The 'gatekeepers' forwarded to me the details of all parents who responded positively to this invitation and I then established phone contact with each of them to obtain informed consent and negotiate a time and venue for the interviews. Approximately six to seven male and female parents from each local authority were initially approached.

To explicitly demonstrate that emerging data are grounded in the field, this study was conducted in two stages. In the first stage, two focus groups of parents were organised, each consisting of four parents. The aim of the focus groups was to identify major concepts used to describe their QOL experiences. The data from the focus groups were used to fine-tune interview guides, which became more semi-structured towards the latter stage of the

interview process in the second stage. This again reinforced theoretical sampling as the data from the focus groups directed further data collection in the interview stage. Development of the interview process is explained later in this chapter.

I liaised with the key people identified in each organisation to recruit parents for the focus groups. Information sheets about the study and consent forms (see Appendix i and ii) were sent to these key people to be distributed to potential participants. The participants who expressed interest in the focus group and met the operational definition of the study were shortlisted and their details were forwarded to the researcher. I followed this up with an email negotiating the time and venue for the focus group. Logistical issues caused a delay between expressing an intent to participate and actual participation in focus groups; thus, I contacted the participants by phone to determine if they were still willing to participate. Two participants who had initially consented were unable to be contacted at the time the focus groups were conducted. One of the challenges that I faced while conducting focus groups was to recruit fathers. Despite considerable efforts to encourage fathers to participate, the two focus groups that were held had four female parents each. Other researchers mention similar challenges in recruiting male parents in the studies examined during the literature review.

As I approached the second stage of the study, I had access to a list of parents, social workers and operational managers who had expressed consent to participate. It is important to note that the social workers interviewed were not necessarily those working with the child whose parent(s) participated in the research interview. While it would have been ideal to pair social workers and parents for interview, this was not achievable in practice because of unpredictable and busy work commitments, sickness and work demands that were of higher priority than participating in a research study. Nonetheless, the data gathered from social workers and operational managers are useful as they provide an important comparative dimension to the parents' experiences of social work services.

The writer contacted each participant by phone or email to arrange a mutually convenient time and venue to conduct interviews. Most interviews were held in the participant's home or the social worker's or operational manager's place of work. To interview some parents I had to travel to locations at which parent groups and children's clubs were held, because this presented their only opportunity to take part in the study.

Several parents expressed difficulties in arranging childcare for their child with autism to enable their participation in the study. A good number of female parents preferred to have the interview completed during school times when their child (ren) was at school. In contrast, many male parents preferred evening times because of work commitments during the day. Among the several difficulties I had in gathering the data was extensive travel times: for example, interviewing one male parent who travelled extensively as part of his work required me to make two six-hour round trips. Parent participants made me aware that they may have to truncate the interview if they were called to attend their child with autism, which is a common scenario in their lives. Four (three male and one female parent) participants who initially expressed interest to participate did not follow through because of changes in their personal circumstances. It was a coincidence that a number of male and female parents who participated in the study were from the same family units. A total of 23 parents participated in the interviews, of which 10 were male parents and the remaining 13 were female parents. Among the participating parents were seven couples; three single parents; and six parents with partners who chose not to participate in the study.

Negotiating interview times with social workers and operational managers was another challenge given the fluidity of scenarios with which they deal; a few rescheduled appointments with me as they had to prioritise their 'duty of care' calls. This meant I made more than a few void trips; on reflection all these experiences made this research journey worthwhile.

A total of 23 parents (13 mothers and 10 fathers), 12 social workers and three operational managers participated in the second stage of the study,

making a total number of 38 interviewees. While careful consideration was given at every stage of the recruitment process to ensure that the parents who participated in the study had a child(ren) with autism, during the interviews it emerged that some participants had a child with other associated disabilities, such as a learning disability. The data indicate that there was no uniform approach to the diagnosis of other co-morbid conditions such as learning disability at the point of confirming the autism diagnosis. Hence, the sample in this study provided mixed responses, with some mentioning their child also had a learning disability and others providing no further information of their child's co morbidities if any. The data from social workers, however, revealed the interesting pattern that a child who has a dual diagnosis of autism and learning disability is more likely to access their service. Hence, it is likely that children of the parent participants had an associated learning disability that may or may not be formally diagnosed. It might be argued that this creates the potential for the sample to be biased given the absence of explicit data from all participants about their child's associated co morbidities. On the other hand, it could be argued that it is feasible that the sample is homogenous, given the weight placed on the presentation of learning disability alongside autism to access their service.

5.8.3 Sample Profile of Participants

Total Number of Participants

Parents of a child(ren) with autism were the main subject of this study. To gain a fuller understanding of parents' QOL experience, social workers and operational managers were also interviewed (see Table 3).

Table 3: Numbers of interview respondents

	Study Local Authority 1	Study Local Authority 2	Study Local Authority 3	Group B
F Parent	4	4	2	3
M Parent	3	3	3	1
Total	7	7	5	4
Social Worker	4	4	4	Not applicable
Operations Manager	1	1	1	Not applicable
Total	5	5	5	Not applicable
Total no. of female parents recruited = 13				
Total no. of male parents recruited = 10				
Total no. of social workers recruited = 12				
Total no. of operational managers recruited = 3				

Age and Gender of Parent Respondents

As set out in Table 4, the majority (19) of parents fall within the age range of 30–50; four parents were aged 50–59.

Table 4: Age and gender of parent interview respondents

Age Range (years)	Female	Male	Total
30–39	4	3	7
40–49	8	4	12
50–59	1	3	4
Total	13	10	23

Ethnicity of Parent Respondents

This study was carried out in the Scottish context. The three selected study local authorities have a large Scottish population with concentrations of people from other ethnic backgrounds (Scottish Government, 2001). Analysing the data related to the ethnicity of the parent respondents is

indicative of this. Seventeen parent respondents were Scottish and the remaining six were British Asian (Pakistan), Black British (Africa), or with another white or ethnic background (see Table 5).

Table 5: Ethnicity of parent respondents (interviews)

Ethnicity	F Parent	M Parent	Total
British/Scottish	9	8	17
Other white background	1	0	1
British Asian (Pakistan)	1	1	2
Black British (African)	1	0	1
Other ethnic minority	1	1	2
Total	13	10	23

Family Units in this Study

As previously mentioned, among the 23 male and female parents who participated in the study were seven family units; that is, both the male and female parent from the same family participated. To minimise the influence of these parents on one other's responses, they were interviewed separately. Also, their interviews were in close succession (with the exception of one family unit where the parents were interviewed on separate days) to minimise the opportunity for them to discuss the research topics and influence each other's views prior to the research interview. Please see the table below for details.

Table 6: Identification codes for parent interviewees and their child(ren) with autism

Child(ren)	Age of Child(ren) (years)	Gender of Child(ren)	Parent(s)	Age of Parent(s) Years	Local Authority/Voluntary Organisation
K	13	Female	Male parent 1 Female parent 1	40–49 40–49	LA1
C	9	Male	Male parent 2 Female parent 2	50–59 40–49	LA1
F	10	Male	Male parent 3	40–49	LA1
FF	8	Male	Female parent 3	40–49	
S	16	Male	Female parent 4 (single parent)	40–49	LA1
J	7	Male	Male parent 4 Female parent 5	30–39 30–39	LA2
R	14	Male	Male parent 5	50–59	LA2
E	14	Male	Male parent 6 Female parent 6	50–59 50–59	LA2
A	15	Male	Female parent 7 (single parent)	40–49	LA2
K	12	Female	Female parent 8	40–49	LA2
A	13	Male	Male parent 7 Female parent 9	40–49 40–49	LA 3
E	7	Male	Male parent 8	30–39	LA3
A	5	Male	Female parent 10	30–39	

K	12	Female	Male	40–49	LA3
J	8	Male	parent 9		
L	11	Male	Male parent 10	30–39	Voluntary organisation
T	9	Male	Female parent 11	30–39	Voluntary organisation
B	12	Male	Female	40–49	Voluntary
W	9	Male	parent 12		organisation
B	5	Male	Female parent 13 (single parent)	30–39	Voluntary organisation

Age Range of the Children with Autism

The age range of the children with autism for this study was expected to be 5–18 years. All but one of the respondent parents had children within the age range of 5–15 years (see Table 7); thus, the sample group recruited closely adhered to the inclusion criteria.

Table 7: Age of child with autism

Age Range (years)	F Parent	M Parent	Total
5–10	5	3	8
11–15	7	7	14
16–18	1	0	1
Total	13	10	23

Gender of the Children with Autism

There has been robust discussion in the literature (refer to Chapter 4 for details) with respect to the prevalence of autism; specifically the higher percentage of boys having this condition compared with girls. As shown in Table 8, 21 parents who took part in the study had a male child(ren) with autism. This supports the literature suggesting that a higher proportion of boys than girls have autism.

Table 8: Gender of child with autism

Gender of Child(ren)	F Parent	M Parent	Total
Son	10	6	16
Daughter	1	1	2
Son + Son	2	2	4
Son + Daughter	0	1	1
Total	13	10	23

Age and Gender of Social Workers

As shown in Table 9, two-thirds of the 12 social work participants in this study were females.

Table 9: Age (years) and gender of social workers

	20–29	30–50	>50	Total
Male	0	2	1	3
Female	2	5	2	9

5.9 Data Collection and Analysis in Grounded Theory

As explained with respect to the Straussian school of grounded theory (1998), one way for this study to operationalise theoretical sampling was to purposively select the parents, social workers and operational managers according to the specified inclusion criteria. Early analysis of the focus group data in this study highlighted issues for further exploration and this also demonstrated that data collection and data analysis were alternating in sequences (see Figure 2).

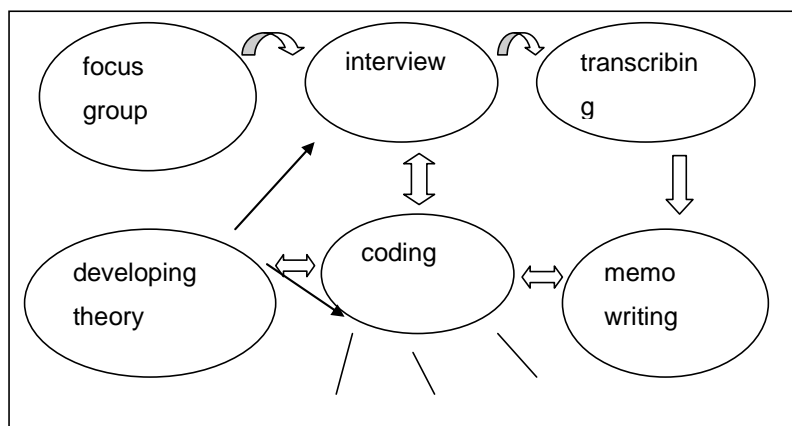


Figure 2 : Steps in developing grounded theory

Figure 2 describes the iterative cycle of data collection (deduction), data analysis (induction) and constant comparison between results and new findings to generate theory (Strauss & Corbin, 1990). The interviews were transcribed verbatim. To facilitate confidentiality, all identifying information was removed from the data, with each participant being assigned a pseudonym. To ensure accuracy of the transcriptions, interview audios were

replayed while re-reading the transcribed interviews. This approach further helped me to become fully immersed in the data. Memo writing and comparative analysis were utilised throughout the study and also assisted in the process of open, axial and selective coding. It is an expectation that data are collected until theoretical saturation occurs; that is, until no new or relevant data emerge (Strauss & Corbin, 1998). Member checking is an important part of validating the data gathered. I ensured this by comparing the data gathered in a previous interview with subsequent interviews and having timely and focused discussions with my supervisors about the data gathered. I had offered the participants the opportunity to review their interview transcripts, but none chose to do so. A few participants maintained blogs (e.g. autistic dad) about their experience with autism. I utilised these web forums to undertake the member checking process.

Experience of Social Workers

Other than three new or recently qualified social workers, the social workers who participated in the study had experience ranging from 5–35 years (see Table 10).

Table 10: Years of experience of social workers

	<5	5–10	>10
Study Local Area 1	1	3	0
Study Local Area 2	1	1	2
Study Local Area 3	1	1	2
Total	3	5	4

5.10 Data Collection Methods

When choosing methods for this study I had to consider their appropriateness for answering the research questions posed. How data are collected will influence which phenomena the researcher will observe; how, when and where these will be viewed; and what sense the researcher will

make of them (Charmaz, 2006). The data collection methods utilised in this study are explained in detail in the following sections.

A variety of potential data collection methods were available and included ethnographic methods, demographic survey, textual analysis, focus group discussions and interview (Cresswell, 2003). Ethnographic methods can be utilised in grounded theory research. However, ethnographic data collection methods such as participant observation would have been more appropriate in a clinical setting, or in a study involving observation of the interactions between two or more participants. Participant observation was not a feasible option as the focus of the study was exploring the parents' QOL experiences via their own telling of their stories.

In accordance with the study's underlying assumption of symbolic interactionism, the participants' perceptions of the reality of their social world were determined to be of greater significance in the development of theory. Interviews would enable the researcher to access in-depth descriptions of the continuous experiences of the participants, in contrast with the snapshot data that would have been obtained through participant observation (Morse et al., 2009).

There are two types of interview: individual or group. These can be conducted face to face; by telephone; through Internet communication; or through other forms of electronic communication (Cresswell, 2003; Fontana & Frey, 2005). Group and individual interviews were used in this grounded theory study; a decision that was supported by the literature (Charmaz, 2006; Kamberelis & Dimitriadis, 2005).

5.10.1 Focus Groups

The focus group can be defined as a qualitative group interview technique that takes the form of in-depth discussions lasting for one to two hours with small groups of 8 to 10 people who are criteria selected (Burchinal, 2007). Focus groups are so called because they begin at a very broad level,

gradually becoming more focused on the topic as the interview progresses. Powell et al. (1996, p. 194) define a focus group as a 'group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research. Focus groups are useful when it comes to investigating what participants think, but they excel at uncovering why participants think as they do'. They help to gather a large amount of data in a short period.

Focus groups were considered an appropriate starting point for data collection in this study for two reasons. First, this method encouraged the participants to reflect on their experiences as a parent of a child with autism while enabling the researcher to gather rich data that were based on the perceptions of the participants, rather than that of the researcher (Denzin & Lincoln, 1994; Kamberelis & Dimitriadis, 2005). Two focus groups (with four participants in each) were conducted at the commencement of this study. The data generated from the focus groups were used to fine-tune the topic guides for the interviews used in the second stage (see Appendix) for topic guides developed for the focus groups).

Focus groups are defined as a valid qualitative research method for gathering information from a number of individuals with common experiences, consequently allowing for the investigation of a multitude of perceptions in an area of defined interest (Beyea & Nicoll, 2000; Minichiello et al., 2004; Nyamathi & Shuler, 1990). In this study, the focus groups provided an excellent forum for the generation of rich, authentic data by capitalising on the richness and complexity of group dynamics (Kamberelis & Dimitriadis, 2005).

A review of the available literature on focus groups indicated that focus groups should ideally consist of 4–12 participants (Jamieson & Mosel Williams, 2003; Kreuger, 1994; Stewart & Shamdasani, 1990). As indicated earlier, each of the two focus groups had four participants. Jamieson and Mosel Williams (2003) and Stewart and Shamdasani (1990) support smaller numbers of participants in that if groups are large, time constraints limit

optimal participation by all members. Difficulty in gathering larger numbers of parents able to participate in a focus group together in the one location at the same time was also an operational rationale for utilising smaller numbers in the focus groups.

As the experiences of parents were relatively unknown at the outset, an unstructured questioning approach was used in the focus groups, while a semi-structured opening question approach was used to open up the focus group discussion. This allowed the participants' responses to guide the interview, rather than the researcher asking set questions that may have led to important perceptions being overlooked or not expressed (de Vaus, 1995; Minichiello et al., 2004). The opening question for the initial focus group was 'What does the term *quality of life* mean to you?'

The setting for the focus groups was a conference room that the participants attended. Careful consideration was given to the appropriateness of this location. If the participants did not feel relaxed and comfortable in the setting, there was the potential that the quality of the data would be affected. In consultation with the participants, it was decided that the conference room was an appropriate venue in which the participants felt comfortable and relaxed. Each focus group lasted 60–90 minutes. Ground rules were agreed in participation for the group, particularly around confidentiality and mutual respect. I observed that the parents utilised the opportunity to empathise and sympathise with other participants and shared their views and experiences. The data gathered using the focus groups were coded to identify the topic guides for interviews. An example excerpt from one of the focus group discussions is as follows:

You just need a break from your child because it's a constant like you're on a train track and you're constantly running [fatigue, respite], you're going through the same routine, the same everyday structure and you can't have a break [monotonous life, disappointed, parenting experience]. So quality of life as a parent is to get to know what reality is all about because you're away from that [isolated, disappointed]. When you have a child with autism, I don't know about all of you but you live in a different world, in a

different bubble, you don't belong ... you lose your friends, your family, your quality of life [areas of life that is affected]. You're just like you're in a prison with your child and there's no way out [restricted]. We ask ... and it's like you're in a little maze and you're trying to find your way out and every door you knock at it just shuts down at you [lack of help and support, support needs]. That's how I feel, I don't know about the other ladies.

5.10.2 Semi-structured Interviews

Kvale (1996) defines qualitative research interviews as 'attempts to understand the world from the subjects' point of view, to unfold the meaning of peoples' experiences, to uncover their lived world prior to scientific explanations' (p. 22). Good practice in qualitative interview needs to incorporate three major elements: good questions, trained interviewer and careful documentation (Patton, 2002).

Semi-structured interviews were used to gather data from parents, social workers and operational managers. Semi-structured interviewing is more flexible than structured interviewing or surveys. Although this technique will have some established general topics for investigation, the method allows for the exploration of emergent themes and ideas rather than relying solely on concepts and questions defined in advance of the interview. It also gives a degree of flexibility to the respondents and is neither tightly scheduled like a structured interview, nor too vague—as in the case of an unstructured interview where the respondent may be unclear what to say and may lose focus, which is not ideal with respect to addressing the research questions posed in this study. Semi-structured interviews also ensure a certain degree of consistency in the questions asked to all respondents. A total of 38 face-to-face interviews were conducted with parents ($n = 23$), social workers ($n = 12$) and operational managers ($n = 3$).

Probing and cross-checking is the first layer of a good interview. Here, questions and topics are tailored to the findings from previous interviews and the findings are validated by cross-checking with other questions and information from other respondents. A good interviewer must be sensitive to

the mood, body language and time constraints of a respondent; listen actively to probe and cross-check whenever necessary; take notes in a non-threatening way; and demonstrate a good sense of humour to manage sensitive issues tactfully.

Careful documentation of the interview should be made to avoid biases and to ensure that interviewees' exact interpretation has been recorded. I obtained consent from the respondents to audio record the interview sessions and gave them the option of turning off the digital recorder at any point during the interview process. An offer was made to send a copy of the transcript to each interviewee as part of the member checking process; however the participants did not appear keen to receive it.

There is a close interplay between sampling, data collection and data analysis in the GTM (Charmaz, 2006; Strauss & Corbin, 1990, 1998). In this study, data analysis directed further data collection strategies. It was this interplay that also saw the interview questioning become progressively more structured in later interviews. The increased structure was the result of theoretical sampling and the need to ascertain specific data from participants in those interviews.

Both the individual and group discussions in this study were audio recorded. While there is continued debate concerning the benefits or otherwise of audio recording interviews (Schreiber et al., 2001), recording of discussions was beneficial for the analysis of the data in this study as it allowed me to focus on conducting the interview, rather than on the process of taking detailed notes (Charmaz, 2006; Schreiber et al., 2001). Audio recording of the interviews allowed for full transcription of the responses verbatim, a process that greatly assisted with the analysis of the interviews as the exact statements made by the participants were available (Sim, 1998). Audio recording of interviews also reduces the risk of a researcher forcing the data based on their own bias (Charmaz, 2006) and reliance on memory.

Once the interviews were recorded, the interviewer transcribed them, rather than seeking to use a transcription service. Again, this helped with achieving a depth of understanding of the data. The experience of this research was that, while time consuming, listening to and transcribing interviews achieved a much more nuanced and deeper understanding of the data. Having a transcribed copy of the interviews allowed consistent immersion in data, permitting retrospective insight into issues that were not immediately obvious during the course of the interviews. Transcription of the interviews also allowed the opportunity to return to earlier interviews as new phenomena were identified; a process that afforded me the opportunity to ascertain the context of the data. This facilitated the use of constant comparative analysis as I had printed a copy of the transcript.

5.11 Piloting

As part of the preparatory phase leading up to data collection, I utilised existing relationships with professionals and parents to obtain feedback about the proposed research questions, information leaflets and consent forms. I conducted a mini focus group (with two parents), two parent interviews, one social worker interview and one operational manager interview to develop group rules for focus groups; be sensitive to the questions and language used in interview tools; and gauge the duration of each interview. Piloting not only assisted me to critically reflect on the potential bias of approaching the study with a practitioner's frame of mind as opposed to that of a researcher, but also facilitated fine-tuning of my research interview skills given that I had not previously conducted research. Feedback was incorporated into the final design.

5.12 Data Analysis

The grounded theorist is an instrument of the research process and as such, data analysis is reliant on the researcher's analytical skills and creativity so that meaning and interconnections in the data can be interpreted to develop theory (Strauss & Corbin, 1998). This study generally utilised the procedure

described by Strauss and Corbin (1998) for analysis of the data; however, the procedural steps were not rigidly adhered to.

5.13 Operational Aspects of Theoretical Sampling and Theoretical Saturation

Grounded theory studies are managed in line with practical constraints. Theoretical sampling suggests that one should select future interviews and data points to test one's emerging theory; thus, exploring the boundaries and diversity of concepts is key. This was practised to an extent when selecting parents, social workers and operational managers. I worked closely with access organisations to gain access to parents from a variety of age groups, ethnic backgrounds and relationship status. The social workers and operational managers who participated in the study also had varied representation in terms of age, gender and experience. However, given that access was negotiated through local authorities and voluntary organisations, I could only approach the participants who had already consented for their details to be forwarded to me, limiting the scope of theoretical sampling in its purist form.

The access organisations also required an anticipated number of participants; this is also a misalignment with the concept of theoretical sampling, which does not begin with a predetermined sample size. It was impossible within the scope of this PhD study, given the framework, time frames and deadlines, to adhere in a strict sense to the theoretical sampling flow of alternating between data collection and analysis. However, I made some explicit procedural and sampling choices to operationalise the iterative cycle of data collection and analysis in a modest way. Staging the data collection process (doing focus groups first, followed by interviews) was one of the considered choices made in regard to this. The first two interviews were transcribed immediately to search for emerging codes and issues that required further exploration in subsequent interviews. As the interviews progressed, they appeared to be more and more structured, indicating theoretical sampling. Sampling a small group of parents who did not receive

social work services (Group B) was another explicit choice to ensure that data were available for negative case analysis (Padgett, 1998).

In operational terms, theoretical saturation occurs when data are not leading to further conceptual development. This is associated with the last stages of grounded theory when the analysis and picture are complete. However, when this actually happens it appears to be subjective, a decision that could be encouraged by the looming deadline of a PhD, time frames stipulated by the organisations granting access, the availability of participants and so on, as experienced in this study. Also, saturation can be problematic because the data can be reinterpreted in new ways.

I attempted to achieve saturation in this study by searching for categories that have the most explanatory powers ('attachment', 'new normal') because the research questions in this study are about explaining and describing the QOL experiences of parents. Glaser and Holton (2004) explain that grounded theory only seeks to present plausible hypotheses that are grounded in the data. Another aspect of saturation is the acknowledgement that the theory developed in this study is one way of explaining the data; there is scope for modification and reinterpretation.

5.14 Using Grounded Theory in the Current Study

It is often difficult to convey the chaos of grounded theory within the structure of a thesis. Barbour (2001) warns novice grounded theorists that an attempt to produce a neat and static account of the grounded theory process serves only to obscure this complexity. Thus, when my supervisors asked me to document how I developed my grounded theory, it was challenging because the process was so laborious, complicated and messy. However, what I have attempted in the discussion below is to explain with worked examples how I approached the coding process.

Strauss and Corbin (1998) advocate several coding techniques to examine interview data at different levels. Open coding, also known as line-by-line coding, is the initial starting point of the analytic process. It fractures the data

and produces a list of themes relevant to the interviewee. Conceptual labels are assigned to every line in the interview transcript to summarise what is being said. Where possible, *in vivo* codes are used to ensure the researcher remains close to the data. The labels used in open coding can also be descriptive. Open coding generates codes in substantial volumes; hence the popularity of coding software such as NVivo. However, I felt disconnected from the data when using a software programme, so reverted to pen and paper. Coding the transcripts by hand was advantageous as it facilitated microanalysis and allowed more of the data to be seen and codes to be assigned simultaneously. This resulted in a more consistent assignment of codes. Box 1 provides an example of open coding in this study for the interview transcript of Female parent 2.

Box 1: Example of open coding

Oh, I had my son, who is older than my daughter and he had a perfectly normal childhood, if that is the right phrase ... he was a precocious child, he did everything in a hurry, he was bright and clever and that was fantastic [sense of what is normal]. So, we anticipated having another child, and my daughter arrived as we were delighted to have pigeon pairs, somebody said to us and I thought that was everything complete [unprepared for disability]. We are from big families, my husband is one of five and I am one of three [desire to have children]. So we anticipated having a big family also [desire to have children]; our experience of childhood was great, of having children I should say, was great [unprepared for disability]. It was only and C had constant infections, constant stomach problems, constant ear problems, that she started not responding to sound, then she, well she walked at 1 and then she started to fall over, go off her legs and as a mother you started to think this isn't right [worry of unknown].

Following open coding of the data, I embarked on a more abstract type of coding known as focused or selective coding. It involves coding several lines or paragraphs of the interview transcript with a conceptual label and identifying the core category or major theme of the research from which the theory emerges (Strauss & Corbin, 1998). These codes were applied in subsequent interview transcripts to test them. For an example of this type of coding, see Box 2.

Box 2: Example of selective coding

I guess, he had eye contact, he was babbling and it just left, he stopped looking at people, didn't want anything to do with anybody (Female parent 2, interview) [coded disappearing skills].

Yeah it was like, when he turned one and a half, he started talking, and he was doing normal things. Then when he turned two, he just went quiet (Female parent 11 interview) [coded as disappearing skills].

Selective coding was also used to identify categories that have similar characteristics (e.g., see Figure 3). The next stage is to identify the relationships among categories by a process of axial coding. Strauss and Corbin describe axial coding as 'the act of relating categories to subcategories along the lines of their properties and dimensions' (1998, p. 123). The aim of axial coding is to add depth and structure to existing categories. Axial coding, the process of 'reassembling data that was fractured (and labelled) during open coding' (Strauss & Corbin, 1998, p. 124), was performed alternately with open coding (Glaser, 1978; Strauss & Corbin, 1990, 1998) (see Figure 4).

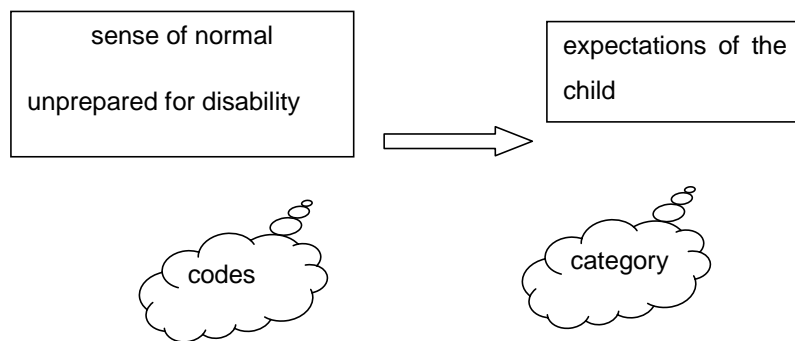


Figure 3: Codes translating to categories

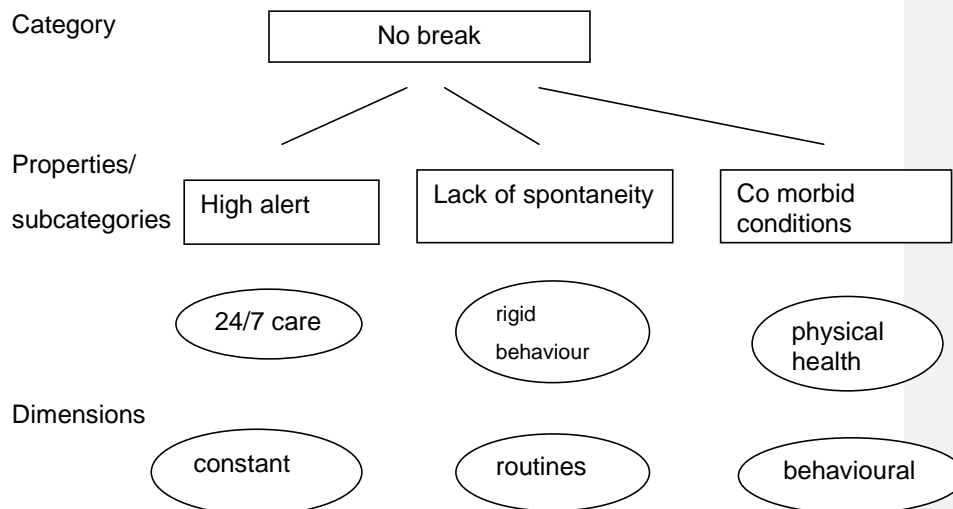


Figure 4: Diagram representing axial coding

Memo writing, Charmaz (2006) proposes, is the pivotal intermediate step between data collection and the drafting of the theory. Memo writing in grounded theory is a crucial method as it prompts the researcher to analyse data and codes early in the research process (Charmaz, 2006; Glaser, 1978; Strauss & Corbin, 1990, 1998). Memos contain 'products of analysis or directions for the analyst' (Strauss & Corbin, 1998, p. 217). Writing of the memos began at the commencement of the study and continued until the completion of the chapters related to the findings. Memos were kept as notes to self, which provided a means of documenting thoughts related to the codes, the emergent categories and the interaction of the categories, as the study progressed. These notes were recorded when ideas arose and took the form of both hand-written and typed notes, depending on when the ideas surfaced. The memos were useful as they allowed the researcher to identify leads to follow via theoretical sampling (Charmaz, 2006; Glaser, 1978;

Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998). They were also useful in supervision meetings. An example of a memo is as follows:

It appears that there are a number of difficulties experienced by this mum when parenting her son. She feels tired and appear to crave for a break. she also appear to be worrying all the time about her son. In that sense, she does not appear to pause, even if she want to; so it is beyond her control. She is on 'high alert'. Rigidity of her son's behaviour makes her life monotonous. Her son is a stickler for routines. Any change to this appear to upset him which further triggers tantrums. She is clearly not happy about that. She can't afford to be spontaneous about any decisions.

The next section discusses ethical considerations in this study.

5.15 Ethical Considerations

Certain key ethical issues emerged before this research commenced, during the process of data collection and after data collection in this study. Ethical guidelines are necessary for any research to ensure that the researcher's individual ethical judgments and decisions are informed by shared values and experience. This study is rooted in the ethical guidelines provided by the Social Research Association and the *Research Ethics and Policy Procedures* of the School of Social and Political Studies (SSPS) at the University of Edinburgh.

The SSPS has its own three-tier ethics procedure 'to ensure proper ethical review and accountability' (SSPS, 2008, p. 1). The first tier consists of a self-audit checklist, 'for proposed research where no special ethical risks have yet been identified' (SSPS, 2008:, p. 1). The second and third tier are for studies 'where a more detailed assessment is required, or where assessment throws up potentially problematic issues that need to be discussed by the Research and Research Ethics Committee (Level 3)' (SSPS, 2008, p. 1). This study cleared the first tier of the ethics procedure involving the completion of the self-assessment checklist and was approved by the Director of the Graduate School.

There were three major ethical issues to be addressed before the research commenced. These were issues of informed consent; anonymity and confidentiality; and safety of researcher and respondents.

5.15.1 Voluntary and Informed Consent

Gaining informed consent was a procedure to ensure that the respondents in the study understood the purpose and objectives of the study, the purpose and limits of their participation and any potential risks they may face. The amount of information required to ensure that research participants are adequately informed varies from study to study. Providing incomprehensible details about the origin of social inquiry is one extreme case of providing unnecessary information; in contrast, holding information that will mislead participants is another extreme way of providing very little information. It is also important to ensure that the information provided is clear and comprehensible (Ethical Guidelines, Social Research Association, 2003). I provided the participants with information on the following issues: purpose of the study; what participation is expected from them; use of digital tapes to record the interaction; whether participants will be identified through comments made by them; and how they can access the results of the study. Separate written consent was obtained from respondents participating in focus groups and semi-structured interviews.

5.15.2 Anonymity and Confidentiality

Anonymity and confidentiality of participants was assured by using pseudonyms in the interview and focus group transcripts. Data were stored in safe lockers and password-protected folders until the end of the study. The prospect of depositing the data transcripts in the university data archive has been discussed with each respondent and decisions will be made only after obtaining written consent from them. Original recordings of data with digital recorders, as well as backup copies, will be destroyed one year after the end of the research.

Confidentiality was guaranteed and the data are only to be used for research purposes. Contextual detailing was limited to prevent the identification of participants through indirect attribution.

5.15.3 Safety of Respondents and Researcher

As topics like QOL and in-depth probing into current service delivery are sensitive issues for parents and social workers respectively, this was discussed in advance with the participants and informed consent was sought. My goal was to ask clear and unambiguous questions to the respondents regarding sensitive issues (Lewis, 2002, in McLaughlin, 2007, p. 64) and to remain sensitive to their reactions. The venue was fixed on mutual agreement to ensure both parties were physically and emotionally safe. As I had to travel to three different study local authorities, I had researched public transport and alternative options of travel if they were needed. I travelled extensively across the various locations in the three study local authorities, making myself flexible and available to meet the respondents at their convenient times. I also made several evening visits to family homes, primarily to interview fathers as they were generally away for work during the day. I informed my own family about my appointments each day and agreed to contact them before and after each interview to confirm that I was safe.

During the data collection process, issues of anonymity and confidentiality were reinforced to the parents and service professionals to alleviate any concerns that their views and opinions might threaten their professional or personal lives. For example, one professional had serious reservations about the interview being audio recorded. I acknowledged these reservations, explained the purpose of recording the interview and reassured her that confidentiality and anonymity would be maintained at all times. She reluctantly consented for the interview to be audio recorded and by the end of the interview appeared to fully appreciate the purpose of recording it. The writer undertook a debriefing session post-interview to ensure the

professional was comfortable with the information gathered and the pace and structure of the interview.

When discussing the ground rules an appeal was made to the respondents in focus groups to keep all discussions within the group. To respect their freedom and autonomy, the right of the respondents to end their involvement in the research at any point of the data collection was made clear at the start. This is because participants may not have understood the purpose of the research until the interview was initiated and then may wish to withdraw. During probing into their QOL experiences, several parents were emotional and tearful. I was sensitive to their responses and offered to stop and restart the interview. The digital recorder was placed within the convenient reach of the respondent, giving them the freedom to stop it at any time.

After data collection, respondents were given the option to obtain a copy of the recorded data as well as the study results. Confidentiality during the publication of results was promised to guard against the 'halo effect' that might encourage the service professionals and parents to try to create a good impression when providing their responses.

5.16 Evaluating the Study: A Perspective

In their book *Discovery* (1968, p. 107), Glaser and Strauss dedicate two chapters to discuss the issue of the quality of the theory produced. They are quick to point out that the indicators used to assess quantitative studies (generalisability, validity and reliability) are not appropriate for studies such as theirs, which aims to generate theory using grounded theory. They write of being sensitive to potential bias; strategies that can be used in the processes and procedures of data collection; and analysis to strengthen the credibility and rigour of the theory generated.

5.16.1 Sensitivity to Potential Bias

It is a prerequisite of all qualitative projects that the researcher is able to see the world from the respondents' perspectives. Padgett (2008) urges

researchers to be sensitive to their own personal and professional experience and be reflective of how this may help or hinder the proposed study. Strauss and Corbin (1998) argue that it is impossible for researchers to disassociate themselves from who they are and what they have experienced. However, with a view to developing sensitivity to the data in the study, I documented my thoughts, perceptions and professional experience as a social worker in a journal entry prior to the commencement of data collection. This was not put aside, but was used during data analysis to develop theoretical sensitivity (Backman & Kyngas, 1999).

Another issue that is particularly relevant in this context is the insider/outsider position. Being a person of Indian nationality, I found undertaking research in Scotland culturally challenging and demanding. Values, belief systems, etiquettes and other cultural elements are diverse in Scotland and differ from those in India. These cultural differences could lead to positionality (the researcher being considered an outsider) and knowledge construction issues (biased ideas creeping in because of cultural influences). There could also be issues with building a trustworthy relationship with respondents.

However, I consider myself to have been in a reasonable position to undertake this research because I had lived and worked in Scotland for several years, which assisted me in acclimatising to the culture, value systems and language of Scotland. Having worked as a professional social worker offered ample opportunity for me to interact and develop professional rapport with parents and other service professionals and keep abreast of updates relevant to this research. This combination of personal and professional experience in Scotland assisted me in reaching out to the respondents during the data collection phase. I was conscious of potential cultural bias and chose to engage in continuous reflexivity to address this.

Another source of bias is the potential for 'the usual suspects' to be involved. These are a group of people who take part in research studies regularly, in that way potentially reducing the involvement of others. This is a tricky scenario as I was in search of respondents who were willing to participate

and contribute to my study and who had consented to their views being used for knowledge generation.

5.16.2 Rigour

Ezzy (2002) refers to rigour as the correct use of a research method, which is discussed as an important aspect of determining quality in theory building research (Glaser & Strauss, 1968). Glaser (1978, 1992, 1998) and Strauss and Corbin (1990, 1998) call for researchers to painstakingly adhere to the proposed grounded theory tools and procedures for data collection and analysis to enhance rigour in grounded theory studies. They recommend careful examination of how data were gathered, what was observed, who was interviewed, what kinds of comparisons were made and how the researcher came to their conclusions. They argue that if the researcher uses the constant comparative technique and carefully saturates their concepts and categories, the resulting theory should be credible:

The researcher believes not because of an arbitrary judgment but because he has taken very special pains to discover what he thinks he may know, every step of the way from the beginning of his investigation until its publishable conclusion ... A field worker knows that he knows, not only because he has been in the field and because he has carefully discovered and generated hypotheses, but also because 'in his bones' he feels the worth of his final analysis. He has been living with partial analyses for many months, testing them every step of the way, until he has built his theory (Glaser & Strauss, 1968, p. 225).

In this study, I conducted two focus groups; the data that emerged were utilised to fine-tune the data collection tool (semi-structured interview schedule) with the language and concepts that parents used to interpret their QOL experience. This sits in tandem with the Straussian school view of approaching the research study with a fair idea, but being open and sensitive to the data on the ground and allowing them to shape the study. A concerted effort was made to recruit an equal number of fathers and mothers to the study, given the under-representation of fathers in research examined during the literature review (see Chapter 4). During the coding phase, I used *in vivo*

codes (an interviewee's exact words; e.g., 'restricting') to maintain closeness to the data. The process of constant comparison between the data sets of different interviews was strictly adhered to in order to facilitate theoretical saturation and theory building.

5.16.3 Credibility

When evaluating the credibility of grounded theory research, emphasis is given to the application of GTM (also referred to as 'rigour' in the previous section) as well as the theory that is produced.

Of special importance to social workers and social work research, Glaser and Strauss (1968) stress that an indicator of the quality grounded theory generated should be its applicability to the real world: 'The theory can be applied and adjusted to many situations with sufficient exactitude to guide their thinking, understanding and research' (p. 233). They add that a theory should have the following four properties to be applied to the field of practice: (1) fit, (2) understandability by those in the substantive area (relevance), (3) sufficiently general to apply to a multitude of situations (workability) and (4) allow the user some control over what is happening in the substantive setting (modifiability). This last property is particularly important for social workers and other professionals who aim to use the theory to intervene in social situations.

It is argued that the research community can easily identify a misfit of theory if a researcher has forced the theory on the data. I anticipate that the research findings will be fed back to the study local authorities, which will further enhance the validity of the theory as they may test it in their own policy and practice context. Social work practitioners in the study local authorities and more broadly may consider applying this theory while engaging further with children with autism and their families. This warrants its relevance and workability and also enhances the credibility of the theory.

Padgett (2008) argues that strategies like peer debriefing and support (in the current case, regular PhD supervision and discussions with other PhD students); negative case analysis (identifying a data set that is different from the rest); rich descriptions of the data; and quotes from interviews can also enhance the credibility of the research study.

5.17 Conclusion

This chapter on research design has outlined the theoretical framework that underpinned the research. It began by contextualising the research problems and consequent research questions. The discussion that followed centred on the ontological and epistemological assumptions, highlighting the closeness of this research to symbolic interactionism, given that person in the environment (parents of children with autism) is the focus. Grounds to position this study as a qualitative inquiry were examined, acknowledging the inductive approach to knowledge generation. The chapter went on to identify grounded theory as an appropriate research methodology, pledging further allegiance to the Straussian school of grounded theory. The next sections of the chapter shed light on the practical framework of this research: location of the study, sample, data collection and data analysis. The chapter concluded with a discussion on ethical considerations, rigour and credibility of the study.

Chapter 6: The Grounded Theory Journey—Parents' Quality of Life Experience is That of Oppression

6.1 Introduction

The research methodology chapter (Chapter 5) described in detail the steps involved in the data gathering and data analysis for this study using a grounded theory approach. This chapter explains how the data sets from the parent interviews and the social worker/operational manager interviews were combined to produce the final core category ('Oppression')—that is, the 'theory grounded in the data'—that defined the QOL of the parents of children with autism in this study.

Therefore, the aim of this chapter is two pronged. The first section briefly outlines the process of combining the two data sets to arrive at the final core category. The second section introduces the finished product of the grounded theory journey undertaken in this research study.

6.2 The Grounded Theory Journey

The aim of this study was to understand in great detail the QOL experiences of parents of children with autism. The concept of QOL arguably identifies what is important and satisfying in human existence. Aristotle made one of the earliest references to QOL with his use of the word 'eudomenia', which means 'good life'. Since the 1980s, this concept has increasingly been researched and used in the field of intellectual and allied disabilities (see Chapter 4 literature review for a fuller discussion.) This study on QOL experiences has made a methodological choice (see Chapters 4 and 5—literature review and research methodology for details) to opt out of using predetermined tools to study QOL, with the intention of approaching the respondents with a 'blank canvas', as suggested by Glaser and Strauss (1967). The development of an overarching theory will be the solution to the research problem; that is, it will provide an understanding of the QOL experiences of parents of children with autism.

This study aimed to create a substantive theory of the QOL of parents of children with autism in the Scottish context. The data were collected by interviewing 23 parents (males and females), 12 social workers and 3 social work operational managers. The interviews were transcribed word for word to avoid missing important details and as a way for me as a novice researcher to immerse myself in the data.

The analysis followed the basic steps of grounded theory, starting with open coding of the data. I read the transcriptions line by line several times, searching for expressions that described the QOL of the parents. The open coding then commenced by analysing every word and sentence to derive substantive codes from the data. Substantive codes were created by using similar words to the initial text. In all, 946 substantive codes were created from parent interviews and 680 substantive codes from social worker/operational manager interviews. Next, substantive codes with similar contents were classified into preliminary subcategories. During this analysis, 24 subcategories were discovered in the data collected from parents and 21 from the data collected from social workers and operational managers. During axial coding, the focus was on grouping the subcategories into the main categories by constant comparison, asking questions about the material and writing memos (Corbin & Strauss, 2008). Subcategories with similar properties were listed under a specific main category (see chapter 5) for examples of open coding and axial coding).

Parents in this study were of the view that living with a child with autism reconfigured the rhythm of their life. It appears that the course of life that they pursued or wanted to pursue was interrupted. The sudden and unanticipated onset of regression associated with the presentation of autism would represent an unexpected blow. The experience for parents is exacerbated because the initial normal presentation of the newborn sets the scene for a normal developmental trajectory for their child. It means that parents have begun to consolidate their hopes and aspirations regarding what they perceive to be a normal life with this new arrival.

The appearance of autism is rather unexpected, making it painful and difficult to reconcile. Changes occur in different domains of parents' lives that are more or less driven by their child's autism rather than being natural or planned. Parents feel disappointed and frustrated that they are restricted in various domains of their life. There is a constant comparison of their ongoing life experiences with what they see as a normal parenting experience or a normal family life. Parents identify gaps between what they currently experience and what they perceive to be a normal experience. Thus, it can be interpreted that the overall experience of living with a child with autism is far from what is perceived to be a normal experience. This study identified various aspects of parents' lives that are affected by autism.

With the use of constant comparison, the perceived 'far from normal QOL experience' was summarised using the following main categories: 'new normal', 'ongoing burden' and 'limited help'.

6.3 Combining the Two Data Sets

As mentioned, this study produced two data sets: (a) from parent participants and (b) from social workers. The two data sets were first analysed separately with the concepts describing the QOL of parents from both points of view (viewpoints of parents and viewpoints of social workers) reported as independent entities. This was done because separate analysis allowed me to better and more clearly represent the personal elements of having a child with autism and the service delivery elements for a family with a child with autism. This is further evidenced in the three findings chapters that follow; two of these chapters report on data set 1 (chapter 7 and chapter 8), and chapter 9 reports on data set 2.

The volume of data generated by grounded theory can easily be overwhelming, as it is difficult to know whether the codes are saturated before the data have been analysed. The researcher can never know if further data collection will provide more information (Hallberg, 2006). Parts of these two data sets were collected simultaneously according to a conscious

choice to ensure that themes emerging in the parent interviews were bounced off in the social worker interviews (e.g., criteria for receiving a social work service for a child with autism). Saturation is based on a subjective decision and is a critical concept in grounded theory, as explained in chapter 5.

It was a challenge deciding when to begin combining the data sets. One possibility was to start from the beginning by open coding the combined data set; another was to begin with the substantive codes. Both possibilities would be time consuming and require repetition of analysis already completed with no guarantee that new information would be revealed. In addition, successfully managing so many substantive codes at the same time turned out to be challenging. Another possibility was to begin with the concepts, but the conceptual level of the concepts felt so abstract that there was a concern that important information would be missed if following this approach.

It was eventually decided to combine the data sets with the help of the subcategories, which were inserted into a new text file. During analysis, it is crucial to avoid forcing the data into preconceived codes and categories (Corbin & Strauss, 2008). The challenge in the combining process was to ensure that the data were not forced into a certain category and that every property and dimension would be maintained in the new combined categories.

Table 11: Concepts that emerged in the two data sets

Concepts in Data Set 1	Concepts in Data Set 2
Expectations of parents during pregnancy	Criteria/threshold of service
Challenges in parenting	Types of services available
Support available for parents	Managing expectations of parents
Relationship aspects	Engagement with the child with autism
Employment	Gaps in the service
Emotional aspects	Training needs of social workers
Stigma	Referral pathways
Services from social work	Multidisciplinary working

Constant comparison and questioning are used to analyse data throughout grounded theory research (Corbin & Strauss, 2008). Constant comparison means, for example, comparing data with a category and comparing a category with other categories (Charmaz, 2006). This was used to find similarities and differences between subcategories. Questions such as ‘What is going on here?’, ‘Who is working here?’, ‘What is this about?’ and ‘What would happen if...?’ were asked when analysing the data sets separately.

When comparing subcategories with each other to combine the data sets, questions such as ‘What is going on in the parents’ lives?’ and ‘Which area of the parent’s life is affected?’ were asked. The subcategories containing similar concepts and contents were placed together. In both data sets, some subcategories had similar names—for example, ‘expectations of parents’ and ‘social worker’s understanding of parents’ expectations’—or quite similar names, for example, ‘restricted experience’ and ‘experience of oppression’. Those subcategories were combined into one category, taking into consideration the properties and dimensions specific to the category. Some

subcategories were given names that described them better, although creating new, more suitable names introduced its own challenges.

During the analysis, all ideas arising from the data were written down. This was done when analysing both data sets separately and when combining them. These memos helped in developing the properties and dimensions of different categories. However, this was challenging as there were many kinds of memos, varying in content, length and degree of conceptualisation.

Diagrams clarifying the categories and their relationships were used. Diagrams are visual devices that portray relationships between analytic concepts and enable researchers to organise data (Corbin & Strauss, 2008). For example, I initially considered a 'tree' as a relevant metaphor: because a tree is a living thing that continues to grow throughout its lifetime, it might be a powerful symbol to represent how the experience of living with a child with autism is in a state of continuous evolution for the parents in the study. The branches and its leaves represent the three main categories ('new normal', 'ongoing burden' and 'limited help') that explain their experiences in further detail. The non-hierarchical organisation of a tree's branches is symbolic of an arguable interpretation of the absence of a hierarchy within the main categories. In other words, each of the core categories contributes by offering a descriptive explanation of the QOL experiences of the parents in this study. The branches of the tree are connected to the tree trunk, analogous to the interconnection of the core categories with the overarching theory (represented by the trunk of the tree). However, I later decided not to proceed with this diagram as the constant comparison process led to alternative propositions that were a better fit to the data.

The final phase of the analysis in grounded theory is selective coding, with the aim of identifying the core category and its links with the others. The core or central category must be abstract; appear frequently in the data; and be logical and consistent with the data. It represents the main theme of the research (Corbin & Strauss, 2008). When presenting the findings and core

category in this study, excerpts from both data sets are used to support the findings (Chiovitti & Piran, 2003).

The conceptual diagram in Figure 5 summarises the grounded theory analysis used in this study. 'New normal', 'ongoing burden' and 'limited help' were the three main categories identified. 'Oppression' emerged as the final core category that qualified the QOL experiences of the parents who participated in this research.

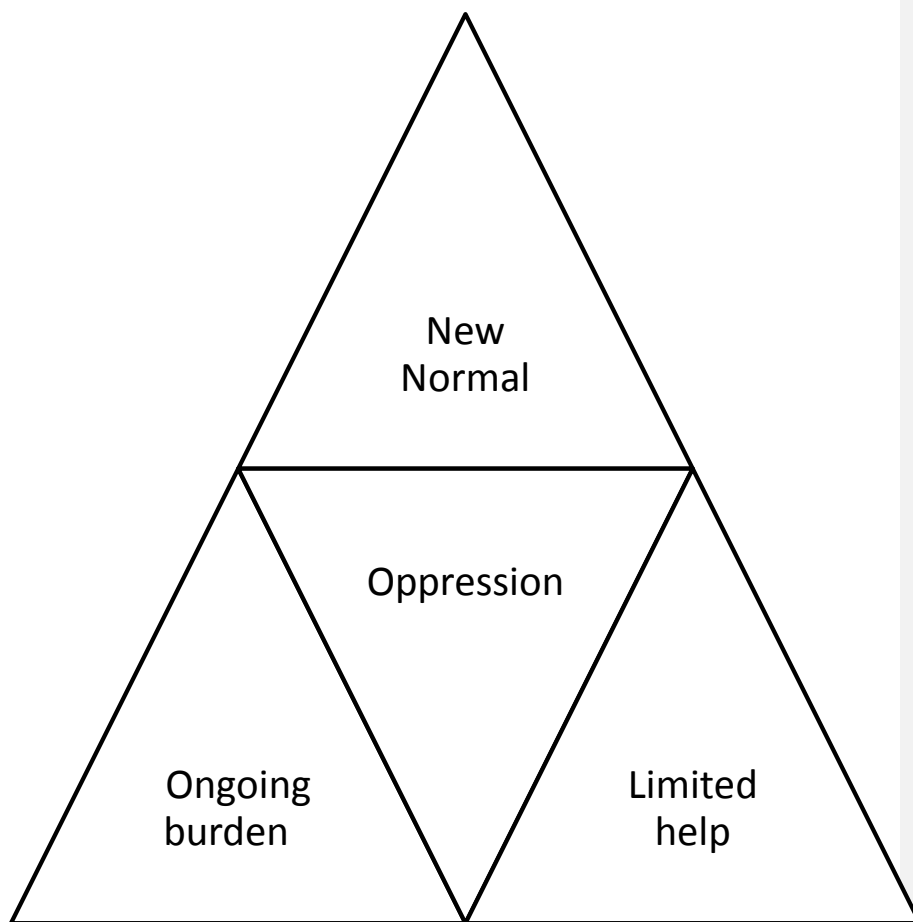


Figure 5: Conceptual diagram of grounded theory analysis

New Normal

For parents in this study, the category 'New Normal' captures a snapshot of the lived experience of parenting their child with autism. The data indicates parents maintaining an internal point of reference of what they believe is a 'normal life'. While parenting their child with autism, they, more often than not, is in a state of comparison of their parenting experience with what they perceive to be the 'norm'. Parents believe they have a new normal, the realisation of which commence with observations of their child leading them

to think something is not right. In their struggle and desperation to make sense of why their child is presenting a particular way, parents indulge in self blame to explain their confusions and uncertainties around their child's behaviours or presentations. While a formal diagnosis is the scientific and objective explanation to their child presentation, the message that this is a life time condition and this is what autism is a daily experience. Their sense of normality is replaced by the urge to be on a high alert, the need to manage the co morbidities, the resistance to any change in the child's routines and the limited interactions happening in the interpersonal space between the parent and the child. Autism and its manifestation in their child's life make parents feel restricted. Their parenting experience, 'new normal' is involuntarily reflected on when parents sum up their quality of life. Data suggests that 'new normal' of the parents is feeding into to an 'oppressive' quality of life experience.

Ongoing Burden

Data indicate that the oppressive experience is not contained just within the parent-child space, but appear to spread to other areas that further defines the parents' quality of life. This is captured in detail in the category named 'ongoing burden'. Parents feel restricted in the amount of time they can set apart for self care or spend with their partners and other children. This, coupled with deterioration in their emotional and psychological health invariably infringe on feeling contented. Parents also expressed dissatisfaction in having restricted capacity to participate in family activities, employment or social activities because managing the care needs of the child with autism appear to be the ongoing need of the hour. The challenging circumstances are further complicated by limited formal (universal services) and informal (family and friends) support and lack of autism friendly recreational activities. Thus, the inevitable and persistent challenges of autism have parents experiencing restrictions in their personal space (self care, emotional health), interpersonal space (relationships, family time), intra personal space (social life, employment). In other words, this category

encapsulates the magnitude of oppression that parents experience in their quality of life.

Limited Help

While there are several avenues of help (medical avenues, therapeutic avenues and so on), this study had specifically zoomed in on the help streamlined from statutory social work services to children with autism and their families. I would like to argue based on the data that the help available through statutory social work services is inadequate, the process and tools for streamlining the help is non engaging and disempowering. This let down by the social work services makes the quality of life of parents, a more oppressive experience.

In combination, these three categories (parents and social workers' perspectives) explain that the quality of life experiences of the parents in this study is that of 'oppression'. The three categories operate dynamically and in association with each other. In the context of the emerging policies and considerable uncertainty due to the ever evolving policy and service landscape of autism, I would like to argue that 'Oppression' has a strong influence on decisions social workers make with respect to assessment of needs and service planning for children with autism and their families.

This category was identified as the best fit because

(a) it captured what autism brings to the lives of the parents, placing the child with autism as the most significant influence in the parents' quality of life experiences

(b) it unveiled the potential for autism to influence (more negatively than positively) in all areas that are important in the parents' life (captured in ongoing burden and limited help)

(c) it captures the dynamic association of the various categories For example, no break (sub category of new normal) explains the findings that the demands of caring for a child with autism lead to parents struggling to get

a break. Not having a break affects their emotional health, relationship with their partner and having 'me time' (captured in the sub category infringing contentment within the category ongoing burden). It also restricts the parents' capacity to have quality family time, to participate fully in work/employment or to enjoy a social life (encapsulated in the sub category restricting participation within the category ongoing burden). Getting timely support from social work could offer the parents a break however that is not the experience of the parents in this study (embedded in the sub category inadequate interventions within category limited help).

The dynamic nature of the model will be explored in more detail in the following chapters as I take the three main categories in turn to show how they have been derived from the parents' and social workers' accounts. I will draw on these categories in the ensuing discussion to make connections between 'Oppression' and the extant literature before concluding with recommendations for research, policy and practice.

Chapter 7: Findings Part 1—New Normal: Vanishing Child, No Break and Non-Reciprocated Attachment

7.1 Introduction

This chapter outlines the parents' views and perceptions around how they made sense of autism to begin with and what it means to be a parent of a child with autism. Analysing answers to these questions assisted in building a picture of the world of the parent as they see it and set the context while describing their QOL experiences. 'New normal' emerged as the category that best describes the data related to this from a grounded theory perspective (see Chapter 5 and 6 for further discussion on grounded theory and the key concepts of the GTM.)

The initial sections of this chapter describe how the participant parents grappled with the concept of autism. All but one parent in the study appeared to have had no personal experience of the world of disability, let alone autism, prior to having a child with autism. Providing a snapshot of their familiarity or non-familiarity with disability appeared to be a natural component of conversations in which parent participants explained the shock of being introduced to autism, and the pain of helplessly witnessing their child 'fade away'. In the language of grounded theory, this segment is coded (refer to Chapter 2) as the 'vanishing child'.

This chapter then identifies some of the specific characteristics pointed out by parents that made autism stand out from other disabilities such as ID or physical disability. 'No break' was used as a code to expand the analysis of how autism influences the parenting experience. The latter part of the chapter focuses on capturing the parents' accounts of their yearning to connect with their child and the thirst for attachment. 'Non-reciprocated attachment' emerged as the grounded theory code to summarise this aspect.

In short, 'new normal' is the overarching category summarising the findings in this chapter. It has three subcategories: 'vanishing child', 'no break' and 'non-reciprocated attachment'.

7.2 Vanishing Child

Long gone is a time when disability was not part of the political and societal discourse in Scotland. This is substantiated by the introduction of generic legislation like the *Social Work (Scotland) Act 1968* and specific legislation like the *Children (Scotland) Act 1995* and the *NHS and Community Care Act 1990*, which have their foundations in the principles of equal opportunities and rights of a child irrespective of their disability. Capability Scotland is one of the pioneering organisations that came about in 1946 to assist disabled people and their families, adding weight to the argument that the concept of disability dates back a long time. However, ASD (see the discussion of ASD in Chapter 2) is a relatively new entrant in the disability cohort, introduced by Leo Kanner around 70 years ago. Even though autism has had its presence in the disability realm since the 1940s, there has been a dramatic increase over the last decade in its prevalence in continental Europe (Lauritsen et al., 2004) and England (Baird et al., 2006), suggesting increased public awareness. It is therefore tempting to think that parents in the study would have known what to expect of autism even before having their own child with autism. However, during the course of analysis it became apparent that this was not the case.

Parents in this study spoke about their expectations and a sense of unpreparedness for a child with autism (coded as expectations); the confusion and frustration of witnessing their child regress (coded as disappearing skills); and attributing the reason for the deterioration of their child to themselves (coded as self-blame). In short, their child seems to be disappearing away from them; hence the subcategory 'vanishing child'.

7.2.1 Expectations About the Unborn Child

The literature suggests that parents have certain expectations when awaiting the birth of a baby. This could be around their role as a mother or father, or potential changes in their life (Belsky et al., 1983). The parents in this study spoke about their expectations of their child later diagnosed with autism.

Thirteen parents in the study had a 'neuro-typical' child who was first in terms of birth order. Neuro-typical is the term used in the autism literature to describe children with typical development trajectories. The remaining parent participants had their only child or all children diagnosed with autism. Their own experience of parenting a child without disability or witnessing others having that experience fuelled their expectations. The former group of parents had their own life experiences with a non-disabled child(ren) as a reference point whereas the latter group appeared to have made observations about how a neuro-typical child should be, based on the experiences of others around them—be they their friends, family or acquaintances:

Oh, I had my son, who is older than my daughter and he had a perfectly normal childhood, if that is the right phrase ... he was a precocious child, he did everything in a hurry, he was bright and clever and that was fantastic. So, we anticipated having another child, and my daughter arrived and we were delighted to have pigeon pairs, somebody said to us and I thought that was everything complete (Female parent 1, interview).

I think sometimes, there is all these responsibilities that a normal child takes, I mean in the early stages, they grow quickly and their needs change very quickly. But a normal child, as they grow up, they become independent day by day (Male parent 3, interview).

The attitude adopted by the parents while preparing for the arrival of a new family member may affect their parenting expectations. Male Parent 9 said that he had a taken for granted attitudes towards having 'healthy' children. Contemplating the probability of having a child with disability appears to be

an uncommon scenario. Other parents in the study expressed similar attitudes:

Very difficult because you just take it for granted that you've got have healthy kids and you never once think anything else (Male parent 9, interview).

Very limited information is available pregnancy-related books about 'children with special needs', according to Female parent 2. It appears there is little focus on disability while expecting a baby. There is a general sense of unpreparedness for a child with disability.

Despite increasing public awareness of autism, the study found that it is certainly not a disability type that parents and medical professionals would instinctively consider while exploring what is wrong with their child. Autism appears to be more complex to comprehend than other disabilities such as hearing impairment or physical disabilities with more obvious signs. In fact, autism in its initial stages was often misinterpreted as a hearing problem:

They were telling us it was glue ear and then they did the surgery for that and I suppose she did have a bit of glue ear but it wasn't a massive problem, we don't think. She was diagnosed as deaf ... At last we had two big hearing aids on her ears (Female parent 1, interview).

Analysing expectations, particularly in relation to the incumbent child, is important to build a 'rich description' (a key concept of grounded theory) of the parent's world. This study found that the onset of autism triggers a sense of disequilibrium between expectations and reality.

7.2.2 Disappearing Skills

Yeah it was like, when he turned one and a half, he started talking and he was doing normal things. Then when he turned two, he just went quiet (Female parent 11, interview).

The presentation and development of the child during the very early stages of their life does not include autistic cues, according to the parent participants in this study. A male parent described his memories of teaching both his

older son (without disability) and daughter with autism to walk. For this parent, the early years with both his children were similar.

Two female parents spoke about the sense of helplessness with which they watched their child progress at one stage (making eye contact, babbling) and regress later (not looking at people, withdrawn). There was a time when they thought their child was developing normally with no cause for concern; but that pattern was not consistent. They were alternating between a state of happiness (child having normal developmental cues) and confusion (child is unwell, inactive, withdrawn). They had aspirations attached to this new family member, expecting them to follow what they described as a normal trajectory of development that is progressive in its course (Berk, 2010). However, parents experienced what is commonly articulated as 'one step forward, two steps backward' with their child with autism:

Then had a whole period of really bad high temperatures and just not wellness. That is the only phrase for me, and she went from being a really active baby and became quite passive, would be the right word, and miserable, depressed, inactive and increasingly withdrawn. And we could get her out of that for periods and then she would vanish back into it again (Female parent 1, interview).

I guess, he had eye contact, he was babbling and it just left, he stopped looking at people, didn't want anything to do with anybody (Female parent 2, interview).

Watermeyer (2009) and Green (2007) speak about families of children with disabilities expecting to feel 'bereaved' at the loss of their child, especially at the stage of diagnosis. However, this study found that parents recognise that the child has been quite severely damaged long before their condition is officially recognised by medical professionals. 'Aching sadness' was an expression used by one male parent in the study to describe the excruciating pain he experienced when he realised that his daughter was losing the skills she had to connect with him (by looking at him, making noises). He realised that his daughter was fading away, she was not the one he thought he had.

The participant parents' emotional state was dominated by anxiety and fear of the unknown, which increased their propensity of parents to develop mental health problems. This supported findings in the literature of increased psychological distress in parents of children with ASD (Kuhn & Carter, 2006).

7.2.3 Self-blame

Parents in this study spoke about witnessing their child emotionally disconnecting from them, not showing any interest in interaction. Not only were they helpless and frustrated, they were equally desperate to know why this was happening. Kanner (1943) promoted the idea of the cold, rigid and distant 'refrigerator mother' as a cause for autism. Although observing a direct interaction between the parent and the child was beyond the scope of this study, there was no indication in the data to suggest that the parents had a cold approach to their child.

What this study found was that parents, in their desperation to decipher the mystery of their child, ended up pointing the finger of blame (cause) at themselves. In an attempt to explain the unexplainable, they fell into a guilt trap, making harsh judgments of their own parenting approach.

This 'self-blame' was particularly noted in mothers (not fathers) whose first or only child was later given an autism diagnosis as illustrated by the excerpts below:

You know here is me trying to be responsive to, I am not getting any response back to it and that hurts because you kind of think, well other kids are developing, is it me? I kept blaming myself. Is it my own fault? (Female parent 3, interview).

He used to like grab my hand and just show me something he wanted and sometimes he would be like talking in a language which I could not understand, making those noises, and then I just thought it was because I live with him just the two of us (Female parent 11, interview).

7.2.4 Summary

This section of the analysis captures how parents begin to make sense of autism as a disability and autism as a reality in their life. Parents in the study did not have a prior understanding of autism, and their expectations of their child reflect that. Parents explained that the initial manifestation of autism was characterised by a regression in their child's development that they were deeply saddened to witness. In their haste to find an explanation for this, parents ended up blaming themselves. In essence, they talked about the child they expected to have and they thought they had as 'vanishing'. This is a jittery start in the context of their QOL experience:

*We just saw her 'leave us' if that is the right phrase, slowly
(Female parent 1, interview).*

7.3 No Break

How do parents experience autism and how is it different from other disabilities? This section of the analysis focuses on finding answers to these questions, which is important in further understanding the specific context of the parents of a child(ren) living with autism. Rutter (2001) argues that the understanding and conceptualisation of autism is changing rapidly. Essentially, it means that parents are dealing with a moving target for which aetiology is unclear and optimal treatment is contested.

There is a pool of family research literature (see Chapter 2 for a fuller discussion) that suggests that parenting a child with ASD is more stressful than parenting children with other disabilities. It was interesting to note the commonality in the choice of words used by the parents in this study to describe their experience. Words like 'difficult', 'challenging' and 'struggling' were common in the vocabulary of both male and female parents. Female parent 2 said parenting her son with autism was a different 'kettle of fish' than caring for her daughter, who was 'neuro-typical', implying it was a rather difficult experience. Male parent 1 stated that it was 'more challenging and

completely different' parenting his child with autism compared with his son who was on the normal development trajectory.

Parents spoke about the specific difficulties of autism that painted a picture of their individual context. It emerged from the study that children with autism have no concept of danger (coded as 'high alert'), adhere to routines religiously with little or no scope for flexibility (coded as 'lack of spontaneity') and have other associated health problems ('co-morbid conditions'). Willingham-Storr's (2014) structured literature search on parental experiences of caring for a child with ID indicates that the challenges of both parent groups are very similar.

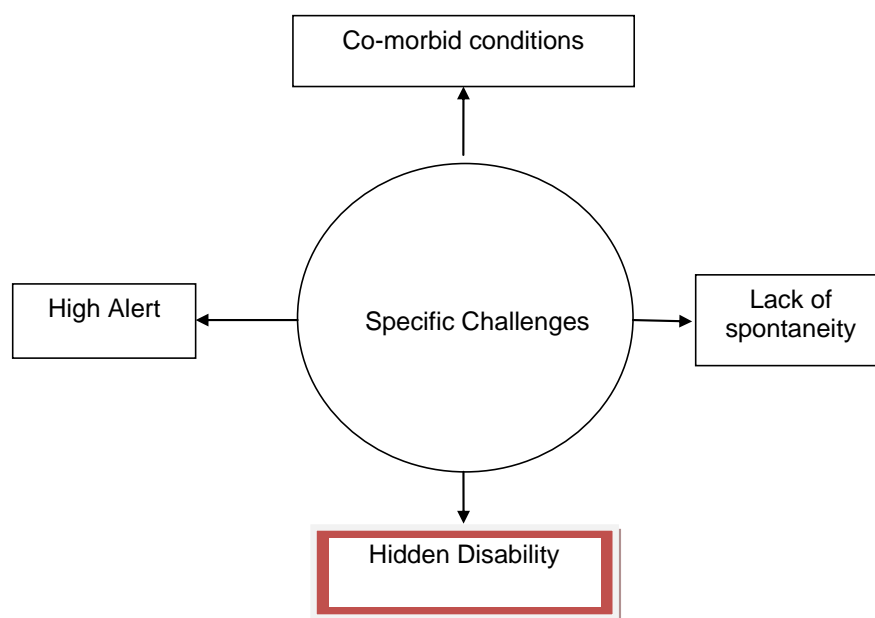


Figure 6: Specific challenges associated with parenting a child with autism

However, this study found that a child with autism does not have any physical signs that would give an indication of disability (coded as 'hidden disability'). That is not the case with other disabilities like Down syndrome

(short neck, flattened face, upward slanting eyes) or other physical disabilities where the visual cues are more prominent (www.nhs.uk, 2014). Hence, parents in this study found it harder to explain their parenting difficulties to others.

It can be inferred that navigating the complex and ever-changing course of autism is exhausting and draining for parents. Caring for their child with autism is constant, it never stops; hence emerged the subcategory 'no break'.

Figure 6 provides a diagrammatic representation of the specific challenges associated with parenting a child with autism.

7.3.1 High Alert

Male parent 2 talked about an incident that happened one day when his son opened the front door in the evening and decided to 'do a runner'; the provocation or reason behind this was still unknown. With the assistance of the police, the parent eventually found his son several hours later. He described this day as the worst in his life, filled with utter panic, desperation and guilt. This is not an isolated story. Female parent 3 spoke about how both her sons with autism had no concept of road safety and would have walked straight into a speeding car if she had been off guard at any time. More stories in a similar vein were identified in the data, implying that parents were worried and anxious about the safety of their child:

I went on holiday, she slept in my bed, she went to the toilet with me, we showered together because I could not dare for one second to let her out of my arm's length because if she escapes she couldn't even tell someone her name (Female parent 1, interview).

I mean there are certain things, for instance, like going out to the park or whatever, I can't take my eyes off T for two minutes. He is not violent; I mean he wouldn't hurt ... but he would go off with ... So in that respect, days out in the park with friends and their kids isn't really the same thing for us just because you are always on high alert (Female parent 12, interview).

This suggests that parents view autism as a condition that can put their son or daughter in situations threatening their physical and mental wellbeing, yet their child's capacity to recognise the risks and act on this is compromised.

The autistic child's inability to learn from experiences and recall the consequences of their previous actions contributes to parents' anxiety:

He absolutely has no awareness of traffic. He has no fear, he still doesn't, that is all challenging. Kids falls, hurt themselves they know not to ... C will do again and again, he doesn't learn from that experience (Female parent 2, interview).

Parents' recognition of their child's limited capacity to safeguard their own wellbeing puts them in a state of 'high alert', constantly scanning for risks and hazards that may threaten their child's safety. It appears to be a self-imposed, compulsive state of mind to protect their child. Female parent 1 in the excerpt above shed light on how her own privacy, self-care and rest time had been consciously ignored to prioritise the safety of her daughter. This made her feel restricted.

7.3.2 Lack of Spontaneity

Autism is a complex developmental disorder, one of its unique characteristics being the presence of repetitive and stereotyped interests and behaviours (Vaughan Van Hecke & Karst, 2012). All parent participants in the study shared stories about their experiences with their child to substantiate this. This study found that the rigidity of the child's behaviour/interests restricted the life of the parents in many ways. To begin with it, it limited the choice of activities that they could participate in as a family or on a one-to-one basis with the child. Male parent 2 spoke about how an innocuous activity like taking a family picture could turn into a distressing event for his autistic son. He explained how he struggled initially to understand the reason behind his son's discomfort; however, he realised several years later that his son was hypersensitive to light and was distressed that day because of the flashlight from the camera. Male parent 4 and Female parent 8 in the excerpts below

explained their inability to go on spontaneous outings or holidays, as this would disrupt the routines of their child(ren), making them agitated and anxious:

That is difficult. I suppose it's a fact that they are both quite limited in their interests and have set routine, so we can't spontaneously decide to go out. You just can't wake up in the morning ... well you can but need to prepare a lot in advance. You can't just suddenly say it's a nice afternoon let's go off to the beach. So you sort of have to get lots of advance notice or they get very anxious (Male parent 4, interview).

When we got there (first holiday with her daughter with autism) I lasted 24 hours. We shared a bedroom. She wasn't used to me being in the bedroom so if I moved the least, but even tried to turn, she would get out of the bed, come out drag me with the bed, put me at the door, open the door and shove me out in the hall. So, you're standing at the hall at two in the morning going where am I going to sleep? (Female parent 8, interview).

The data suggested that the children with autism thrived more in familiar and predictable environments and routines. Hence, preparation and planning was key to minimising distress and distasteful experiences with the child. In reality, it was virtually impossible to plan and prepare for all eventualities. The study found that this was overbearing and, more often than not, restrictive on the life of the parent.

7.3.3 Co-morbid Conditions

Hock et al. (2012) in his literature review, identifies that children with autism have a higher incidence of physical and mental health problems. Three parents in the current study spoke about other medical conditions that coexisted with their son's or daughter's autism:

Going into anaphylactic shock at 10 months, he is allergic to egg, allergy to nuts, anaphylactic allergies, so in addition to autism he has got these allergies, so EpiPens have to go everywhere with him (Female parent 2, interview).

I could get a bit upset now, not really because of S's autism, it's more his heart condition and what happened to him that upsets me (Female parent 4, interview).

She had recurring bowel problems, we got a dietician to help us out with her diet, private dietician, and we joined a couple of autism projects which analysed her bowels which no medical provision had thought to even try. Some children have chronic diarrhoea; that is how it is (Female parent 1, interview).

The aforementioned co-morbid conditions were related to the child's physical health, but behavioural issues were another cohort of conditions identified in the study that coexisted with autism. Being physically animated (e.g., biting, pulling hair) towards self and others was a common difficult behaviour highlighted in the study.

Female Parent 2 gave a graphic account of the extent of behavioural challenges presented by her son:

Ripping clothes, ... he rips T-shirts and socks, shirts, pulls your hair, bites you, when he is outside having a tantrum, he is throwing himself on the ground and you are scared because we don't know what he is going to be doing next (Female parent 4, interview).

Self-harming is another alarming behaviour that heightened the anxiety of the parents in the study:

She's got severe self-harming behaviour, so every single day is a challenge with K. It's not all bad, I'm not saying it's all bad, but it's very challenging. She has got her moments when she can cut herself ... I've got strategies in place like I know certain things that kick her off so I try to avoid them or try a desensitiser or warmer, like if there's a change, we are going somewhere or sometimes she's so sensitive to smells and noise that can really cause her distress (Female parent 8, interview).

The autistic child's lack of sleep was yet another behavioural challenge that puzzled the parents in the study:

I suppose I just want an existence that is mild, I should be able to achieve that with her going to school, but you can't

[work] if you have been up all night (Female parent1, interview).

Co-morbid conditions, whether they are related to the physical health or mental health of the child, were concerning to the parents and the study found that it certainly made parenting more difficult. It also affected parents' mental health. These findings are similar to those reported by Baker-Ericzen et al. (2005) and Lecavalier et al. (2006) who argue that the autistic child's behaviour increases parental stress and mental wellbeing. Closer analysis of the data reinforced the importance of being sensitive to the child's specific needs (e.g., being sensitive to certain smells, noise), which can be useful knowledge to help manage these behaviours more effectively.

7.3.4 Hidden Disability

The child with autism does not necessarily have facial features or other physical characteristics that would give visual prompts to suggest that the child has a disability. The study found; therefore, that societal expectations to comply with the norm are far greater for the child with autism than other disabilities. Female parent 3 articulated this very clearly in the excerpt below:

Because they just see our child as a normal kid and you have to blend in. Nobody has understanding. Like I said, with a Down syndrome child or a physical disabled child, they treat them differently. But if I am with an autistic child, outside they look normal ... People look, and go well, what is wrong with them. They just look at them physically and they can't quite understand what is wrong with them (Female parent 3, interview).

Male parent 1 described an incident experienced by his daughter in the supermarket that is relevant in this context:

They were queuing up to check out and our daughter who has a sort of habit of grabbing some sweets and stuffing in her mouth and she grabbed some nuts and before we paid or anything she was stuffing in her mouth. She chewed the stuff up and she was going through a bad drooling phase, so she sort of drooled out the sort of chewed up nuts stuff which then landed on the conveyor belt at the checkout. And there was a woman just behind, she kind of just went ... erh ... like

that ... obviously hadn't got the wit to recognise that this child, that there was something wrong with them (Male parent 1, interview).

This story along with other similar accounts in the study indicate that autism is a hidden disability. The argument in the literature (see Chapter 4) literature review for fuller discussion) that the public awareness of autism is increasing is questionable in light of this finding:

The very strength, I mean we've been up against it. I think one of the things is when people don't know because autistic children look normal and the people who know and that's neighbours and friends we do make allowances and we've always been very, very upfront (Female parent 12, interview).

7.3.5 Summary

This study found that caring for a child with autism is certainly different from parenting a neuro-typical child; however, there are similarities to parenting children with other disabilities. Male parent 2 gave an example to put this in context:

It is 10 times harder trying to teach a child with autism because you have to do one step at a time, one small tiny chunk, learning, the best example I can give is brushing your teeth, first you have to get his brush, then get toothpaste, take the lid off, get the toothbrush, step 4, put the toothpaste on, step 5, brush your teeth, step 6. ... He learns everything in small chunks and then you add it on, hopefully seamlessly, we have done the same thing for toileting and everything, but it is time consuming and frustrating (Male Parent 2, interview).

The emerging findings suggest that the parenting experience of the respondents in the study was intensive and time consuming. In addition to the various dimensions of caring for an autistic child (high alert, lack of spontaneity, co-morbid conditions, hidden disability), which restricted the spare time they could potentially have, there was also a predominant perception that they should never contemplate being away from their child(ren).

The data suggest that this was primarily because of the parents' lack of confidence in entrusting the care of the child to someone else because of the multitude of complexities that autism possesses. This lack of trust was more apparent in the female participants of the study who appeared to be more hands-on and to spend longer hours with their child with autism, than did fathers. There was a constant prioritisation of the child's needs over those of the parents.

The data also revealed that parenting responsibilities were very demanding and more or less constant. Parents in the study drew parallels with the differing developmental trajectories of autistic and neuro-typical children to highlight this. The latter group go through more or less clear transitions to develop the skills to be more and more independent. However, that seems to not be the case for the parents' children in this study. It became apparent from the data that the pattern of dependency of the child with autism on their parent was a recurring one, suggesting that their intense caregiving responsibilities were likely to continue:

You have got essentially very restricted ability for the child to do things for themselves. So, your parenting experience is fundamentally different (Male parent 2, interview).

In short, the data that emerged from this study explained the specific difficulties associated with autism (high alert, lack of spontaneity and co-morbid conditions) and highlighted the hidden nature of the disability (hidden disability). The data also revealed the parenting strain associated with caring for a child with autism and showed that it is time consuming, demanding and constant. Hence, the parents in the study did not appear to get a break from their parenting role, which underlined their QOL experience as restrictive:

Every day you are just surviving to look after her, because I'm on my own and it's sad, you know 24/7 I'm there all the time (Female parent 8, interview).

7.4 Non-reciprocated Attachment

John Bowlby (1973) in his ground-breaking theory of attachment, more commonly known as 'attachment theory', postulates that attachment is an important component of human experience from the cradle to the grave. Bowlby (1951) defines attachment as a 'warm, intimate and continuous relationship between the mother (caregiver) and the child that gives them both satisfaction and enjoyment'. Attachment theory is used by researchers to explain an adult's wellbeing by determining how happy they are in a family relationship (Mikulincer et al., 2001).

Understanding the attachment experiences of the parents to their child with autism will further expand the specific context of how parents experience autism and shed light on the quality of bonding experiences with the autistic child. These experiences will inadvertently contribute to the sense of parents' wellbeing, thereby affecting their QOL experience.

Following the data analysis, it emerged that male and female parents struggled to communicate with their son/daughter (coded as one-way conversation). While the struggle to facilitate play with their child with autism was an issue for male parents (coded as interactive play), the dearth of emotional reaction from their child with autism (coded as cold response) was painful for the female parents in the study. Hence, it would appear that the overall attachment and bonding experience of the parents with their autistic child was incomplete because there was very little or no response from the child to acknowledge, engage or reciprocate the efforts made by the parent to connect with them (subcategory: non-reciprocated attachment).

7.4.1 One-way Conversation

Limited or no verbal communication emerged as a major stumbling block for parents when trying to bond with their child. Wing (1994) identifies deficit in communication skills as one of the 'triad of impairments' of ASD. Unable to have quality verbal interaction with their child was frustrating and

disappointing for both the male and female parents in this study. The absence of language affected the quality of verbal interaction (can't teach, can't explain) they could have with their child.

The data on communication issues shed light on the frustration and disappointment of parents not being able to have a conversation or interaction for which they hoped. Howe (2005) argues that because of impairment, the ability to clearly communicate their mental state is compromised for children with disabilities. The parents appeared to feel anxious that they did not always understand the needs of their child. There was recognition among the parents that it was several times more frustrating for the child with autism not to be able to communicate their needs appropriately.

The most challenging thing without a shadow of a doubt is communicating because without communication you can't teach, you can't explain, that is the worst part (Female parent 2, interview).

Quality of conversation was affected because of the unresponsive state of the child. Also there was less scope to exchange feelings, thoughts and emotions with each other. Conversation was primarily one way, initiated by the parent. Baron-Cohen et al. (1985) considers that children with autism suffer from 'mind blindness' because they cannot understand why their parents are attempting to speak to them in the first place:

Trying to explain something or have a conversation, we will not generate a conversation with him, so that is limiting again. It is not fulfilling, because you are generating an answer for him. Conversation is not two way, it's one way; he is not receptive (Male parent 2, interview).

SIGN and the Picture Exchange Communication System (PECS) were the popular alternatives for verbal communication used by parents in the study: 'He is now a brilliant SIGNER', said Female parent 2. Even with alternative communication techniques, conversation was superficial because the answers were generated by the child who was not showing an interest to

communicate in the first place. Hence, the entire conversation process became stressful and boring, negatively affecting the attachment experience.

7.4.2 Play

Male parents spoke about doing ‘fatherly things’ to bond with their child with autism. Playing with their child appeared to be a father’s preferred way to connect with them, but the study found that engaging an autistic child in a play activity was difficult; sometimes near impossible. This difficulty could again be related to the theory of mind (Baron-Cohen et al., 1995) where the autistic child cannot understand what play is to begin with, let alone knowing the rules of the play or how to participate. This can trigger significant attachment issues between parents and child:

The negative ones outweigh the positive ones because of circumstances, getting your hopes up, expectations are getting crushed down, so you tend not to try anything slightly different all the time. We do play with what we want; we do try and use things like mp3 players and stuff. There is not a fail-safe method of getting him to participate in any given task ... But in terms of normal everyday stuff, you can’t seem like a neuro-typical, fatherly, because we don’t do a lot of things together (Male parent 2, interview).

I mean we couldn’t go on a skiing holiday for example because we have got one child that isn’t going to be able to ski (Male parent 1, interview).

7.4.3 Cold Response

More than half of the female participants in the study spoke about their child being in a state of emotional vacuum, hence not reciprocating emotionally. The data suggested that the female parents were disappointed and hurt by the cold response from their child. They yearned for the child to acknowledge their presence and have a warm interaction with them. Unfortunately, autism is a condition characterised by difficulties in interacting with others, as children with autism are unable to decipher the verbal and non-verbal cues of engagement to reciprocate a response (Baron-Cohen et al., 1995).

I have not seen C all day, he just be screaming because the car has stopped, no recognition that he hasn't seen me all day and it was good to see me, he is like move the car, I am not happy, that was difficult to deal with as a mum, because you weren't getting nothing back (Female parent 2, interview).

And he wasn't a hugging baby or respond to me at all. So for me it was like having a ... you know having a 'dead child'. I kind of ... I know he is not ... that is the way I felt, like talking to a brick wall. You know here is me trying to be responsive to, I am not getting any response back (Female parent 3, interview).

Female participants experienced pain, frustration and disappointment. The attachment experience was made sour, affecting their sense of wellbeing.

7.4.4 Summary

'Theory of mind' (Cohen et al., 1995) and 'triad of impairments' (Wing, 1994) potentially substantiate why parents in the study had an unresponsive interaction from their autistic child when they attempted to have a conversation, engage in play or experience an emotional connection. The study found that bonding experiences were far from satisfactory: parents felt rejected by their child and had an element of guilt triggered by the thought that they were doing something wrong. This suggests that parents experienced non-reciprocated attachment, which was less rewarding given the day-to-day challenges they faced when parenting their child with autism. The strains of attachment therefore infringed on their QOL experiences.

7.5 Conclusion

The following account from Female parent 1 sums up the emerging findings in this chapter:

You just need a break from your child because it's a constant, like you're on a train track and you're constantly running, you're going through the same routine, the same everyday structure and you can't have a break. So quality of life as a parent is to get to know what reality is all about because you're away from that. When you have a child with

autism, you live in a different world, in a different bubble, you don't belong ... you lose your friends, your family, your quality of life. You're just like you're in a prison with your child and there's no way out. We ask ... and it's like you're in a little maze and you're trying to find your way out and every door you knock at it just shuts down at you (Female parent 1, interview).

Figure 7 provides a pictorial representation of the overarching category, subcategory (property) and codes (dimensions) that emerged using the axial coding process of grounded theory analysis.

This chapter has pulled together the data that offered a rich description of the world of autism through the eyes of the parents. By detailing the specific context of the parents in this study, I have given importance to the parent participants who are convinced that living with a child with autism is like entering a parallel world: parallel to what they perceive as a normal life with a neuro-typical child; as far as they are concerned, the autism bubble is their 'new normal', which emerges as an overarching category with three properties (subcategories).

The analysis began by exploring how parents started to make sense of autism. The parents described watching their child vanish away slowly; hence, 'vanishing child' became the first property (subcategory) and the following dimensions assisted in understanding its context in greater detail: (a) expectations of the unborn child, (b) disappearing skills and (c) self-blame.

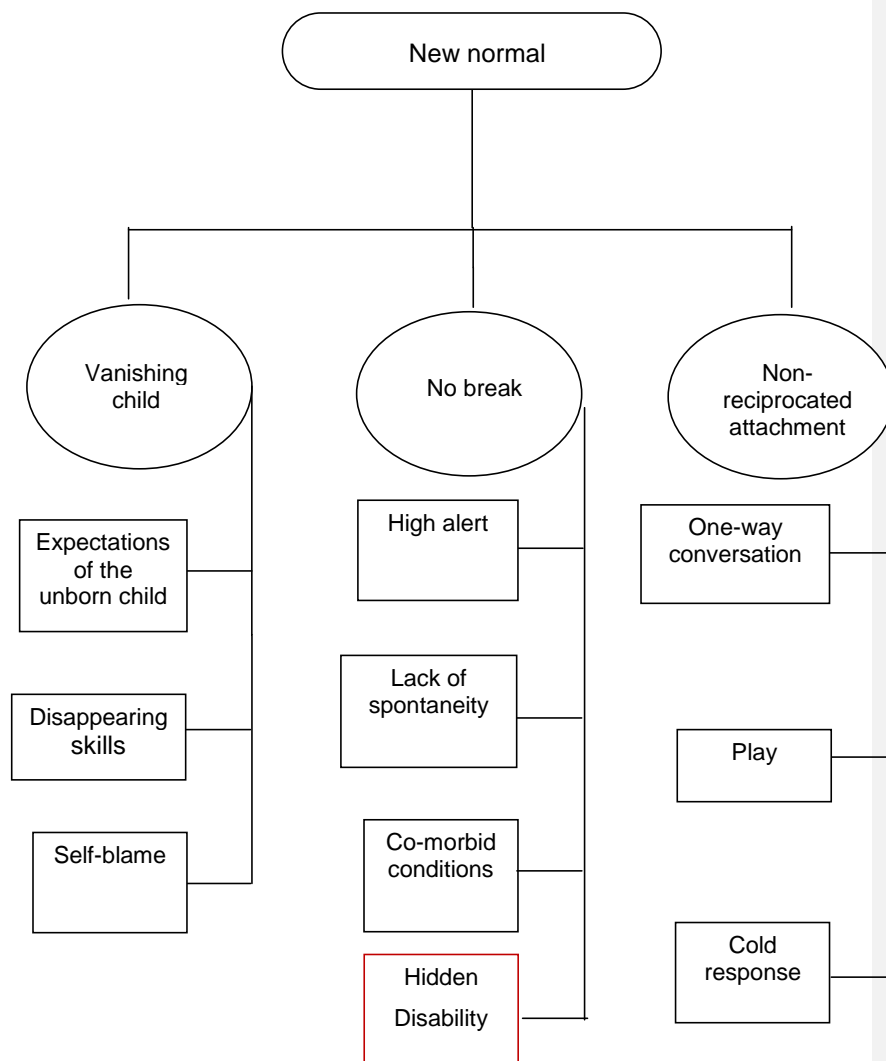


Figure 7: Properties and dimensions of 'new normal'

The second property (subcategory) 'no break' explained in more detail what parents see as some of the specific challenges that autism brings and what makes autism different from other disabilities. These findings were

contextualised in the following dimensions: (a) high alert, (b) lack of spontaneity, (c) co-morbid conditions and (d) hidden disability.

‘Non-reciprocated attachment’ was the third property (subcategory), which describes the attachment experiences of the parent respondents with their child with autism. It was better understood by expanding on the following dimensions: (a) one-way conversation, (b) play and (c) cold response.

As discussed in chapter 6, New Normal provides a personalised and subjective take of the oppression that the parents of children with autism experience; it provides insight into how autism influence their lives; The next findings chapter explain in further detail the expansion of the oppressive experience in several areas of the parents' lives.

Chapter 8: Findings Part 2—Ongoing Burden: Infringe Contentment, Restricts Participation, Limited Opportunities

8.1 Introduction

The previous chapter summarised the 'world of autism' as seen through the eyes of the parents. It offered a rich description of the autistic context of male and female parents in the study. Parents preferred to describe their life with a child with autism as a new world or new normal that in their view has little to no parallels to the world of parents with neuro-typical children. This study found that the new normal was a difficult and restrictive experience for parents.

This chapter focuses on expanding in greater detail on the parents' QOL experiences in the context of living in the world of autism. Through iterative analysis of the data, this study aims to clarify the different aspects of the parents' QOL that they identify as affected by autism. 'Ongoing burden' is the category that emerged to summarise the QOL experience of the parents in the study:

The quality of life is definitely deteriorating; no other people have similar things with normal neuro-typical kids. That is manageable. That is life. Whereas with autism, it is a harder life (Male parent 2, interview).

Our quality of life is a daily burden (Female parent 1, interview).

The first section of this chapter presents findings that consolidate how autism infringes on parents' sense of contentment in life. Coded as 'infringe contentment', parent respondents explained that caring for their child with autism left them drained and exhausted (coded as 'me time'), triggered emotional and psychological repercussions (coded as 'emotional health') and affected their relationships (coded as 'relationship issues').

The study also found that autism places restrictions on parents' sense of participation in life, coded as 'restricts participation'. The parents' definition of participation included spending time with the family (coded as 'family time'), being employed and contributing to the family and society (coded as 'employment') and being part of a social circle (coded as 'social life').

Coded as 'limited opportunities', the final section of this chapter sheds light on the difficulties experienced by parents from universal services like health and education (coded as 'formal support'), limited options of help from family or friends (coded as 'informal support') and lack of leisure/recreational activities or platforms to engage a child with autism (coded as 'activity options').

In summary, 'ongoing burden' emerged as the main category. The three subcategories 'infringe contentment', 'restricts participation' and 'limited opportunities' encapsulate explanations regarding parents' experiences.

This chapter also highlights the emerging gender differences in the study.

8.2 Infringe Contentment

Studies in the area of autism often focus on evaluating its effects on children, but not their parents (Payakachat et al., 2012). In a rare study of parents of children with ASD, Karst and Van Hecke (2012) speak about the importance of having a dominant focus on measuring parents' health; that is, stress and anxiety. They further highlight that a drawback to this approach would be an oversight of other aspects of their QOL, such as the effects of caring, family functioning and so on, if these were not considered. Diener's (1984) popular work on subjective wellbeing provides one of several remedies to address this drawback. Subjective wellbeing evaluates the lives of the individual in general. Life satisfaction or contentment is one of the three inseparable elements in Diener's tripartite model of subjective wellbeing. The ease of use and low administration costs make life satisfaction scales popular in social and policy research; however, the criticism remains that this only tells one part of the story and provides one type of information (Eckersley, 2009).

Using QOL instruments instead is a potential alternative; however, lower sensitivity to the very specific context and particular problems are flagged as a disadvantage (Payakachat et al., 2012). The present study ruled out the use of any predetermined tools and aimed to tease out specific aspects in the parents' lives that infringed on their sense of contentment.

The previous chapter provides a description of specific difficulties in caring for a child with autism, making the caring aspect prolonged and multidimensional. This study further identified that parents struggled with not having the time and energy to care for themselves ('me time') and the effects on their mental wellbeing ('emotional health') and relationships ('relationship issues').

8.2.1 Me Time

This study supports the finding in previous studies (Abbeduto et al., 2004; Baker et.al., 2002) that the demands of caring for a child(ren) with autism are high and require much patience, effort and time (see Chapter 2 for details). This takes us to a discussion of rest and self-care. It is unsurprising that male and female parents used words like 'burden', 'daily burden' and 'ongoing challenge' to describe their context. However, there were some interesting gender differences.

Of the several specific challenges experienced by parent respondents, interrupted sleep pattern of the child was highlighted as a common problem by most female parents in this study. In contrast, only two male parents identified sleep issues as an explicit challenge. It emerged that the children with autism struggled to settle in the night and at times ended up co-sleeping with their parents, as this minimised disruption to the rest of the family (e.g., siblings):

*He wasn't sleeping as well, I was up all night, up all day ...
was always in my night clothes, I was never out and about
(Female parent 3, interview).*

C didn't sleep, he would have C up all night, so he would end up beside us ... C not sleeping, I would say had a much bigger effect on our mental health than the fact, at that point, he had autism. That was complete torture. We both worked at that stage and we were up more than half the night (Female parent 2, interview).

This finding provided further evidence for one of the main reasons for the physical exhaustion associated with parenting a child with autism, as noted in other studies (Benson & Aman, 2004; Couturier et al., 2005):

I can look back now and see he was horrendous sometimes, or lack of sleep, kept up during the night which he still does but not to the same extent back then I mean some nights he wouldn't sleep. So you will have lack of sleep yourself (Male parent 9, interview).

However, the greater emphasis on disturbed sleep by female than male parents could also be interpreted as meaning that the female parents did the major share of direct caring of a child with autism, whereas male parents focused their energy more on the indirect aspects of caring: finances, working to maintain the family and other day-to-day responsibilities. A variant of this finding was that a few couples in the study spoke about sharing the direct and indirect caregiving responsibilities in fairly equal proportions.

Another aspect of autism that differentiated the parenting experience from other disabilities was the sensory issues. Both male and female parents were on the same page in this regard. Given that autism is a hidden disability, the child's hypo- or hypersensitivity to sensory stimulation (visual, auditory, touch and so on) and sensory seeking behaviours triggered behavioural responses that could be viewed as awkward or inappropriate (Miller et al., 2007):

God can you not stop from making a noise. And people with darker skin, he is fascinated with people with darker skins and new born babies ... there was a coloured girl with shorts on and he kept on touching her legs ... And I explained to the mum and dad but they were not happy about it at all ... his friend O, loves O, he is in his class, and all he spoke about all week is O's feet, I know O's feet. He has never seen his feet I don't think, but he is dying to see his feet (Female parent 4, interview).

His behaviour was really bad, really difficult. You know, screaming, tantrums ... because people just think well it's just a toddler having a tantrum but now he's 14. If he has one, people are looking ... you know, and I find that quite difficult (Male parent 9, interview).

Kanner (1943, p. 245) describes that sensory aversion is a coping strategy of the child with autism to control or predict the sensory input from his environment so 'the child can happily make as great a noise as any that he dreads'. Sensory seeking behaviours (touching feet) displayed by the child make the sensations predictable and self-selected (Gomot et al., 2008). These sensory behaviours are difficult for parents to handle as are reported in this study. They can also elicit unfavourable reactions from others in the immediate environment. While sensory issues could be viewed as a stress-diffusing mechanism for the child, they appeared to be a strain-inducing phenomenon for the parents in this study. Parents also anticipated that the child's unique behaviours might be upsetting and unmanageable for anyone else caring for them, preventing parents exploring alternative care arrangements. This was a major part of the daily challenges of dealing with autism, leaving the parents feel exhausted and drained.

Male parents in the study identified the child's inability to learn and be independent as another aspect of the daily burden of caring for a child with autism. Although a handful of female participants also alluded to this, male parents viewed this as an autism-specific trait that made caring for the child a prolonged and enduring process. Parents stated that in the case of physical disability or hearing impairment, aids and adaptations can facilitate independence, which was not the case in autism:

I suppose you kind of think before you have children but that as they grow up you can watch them become more and more independent, do more things themselves and that process hasn't ... They still need a lot more hands-on care ... It's just a fact. It is very, very exhausting and hard work (Male parent 4, interview).

As they grew, obviously, we were expecting the children to be more independent. They were not. They were dependent upon us, still they are (Male parent 3, interview).

This study found that there exists a yearning in all parents to have 'me time'. It transpired from the data that there is a need for physical me time (rest) and mental me time:

Ok, I would absolutely love to have some time, any time to myself. That is my biggie. In ways, I think it would be really nice to go away a couple of weeks even on my own, I don't know if I could (Female parent 2, interview).

It can become a real burden and it is a real task, because you still have needs of your own which you have been putting right at the back of the queue because your first priority is your kids (Male parent 2, interview).

Constant prioritisation of the child's needs over the parents' own needs was evident in the study. Limited scope to find time for themselves summarised the individual 'strain' (also referred to as burden by many parents in the study) that parents experience with autism. The concept of 'me time' also shed light on how the intensive and persistent parenting required for a child with autism can infringe on parents' capacity to feel contented in their lives.

8.2.2 Emotional Health

'It is more challenging full stop', said a very emotional parent during one of the interviews. It unfolded from the very early stages of this study that there was a huge emotional investment associated with the parenting experience of the respondents. This may explain why I witnessed moments of tearful recollections; there were often frustrating undertones in their voices and periods of meaningful silence. It was interesting to observe that the male parents appeared somewhat reluctant to discuss the aspects of their emotional health, unlike their female counterparts.

Parents in the study mentioned health as one of the important aspects for their QOL. Further analysis of the data crystallised the discussion around their emotional health, as there were very few data in the study that reflected the physical health of the parents.

It was evident from the data that from the very first moment of parents having this strange sense of 'something is not right' with their child, anxiety and worry set in. In the initial stages, the anxiety was around the confusion, the uncertainty and the lack of awareness of autism. Post-diagnosis, parents appeared to worry about how best they could meet the needs of the child. Part of the worry may have been around getting it right in terms of their parenting approach and obtaining appropriate services to meet the needs of their child; another set of worries centred around how their actions or decisions, or incidents in their life may affect their child. However, the data suggested that worrying about their child's future—particularly when the parents are no longer there to care for them—was the most predominant. All parents in the study shared their experience of worrying about their child's past, present and future. The worry was so constant and real it appeared to be more or less a vicious cycle:

I constantly worry about, from day to day, are we doing enough for him, how can he tell us his feelings, all his kind of issues to a what is going to happen to him when something happens to me. That is a huge worry (Female parent 2, interview).

I actually thought it's really very tough. It was really very tough when, and I think after, A specifically. I was depressed (Female parent 5, interview).

Coping was another related concept that repeatedly emerged from the data. The data suggested that all participants in the study coped at varying degrees. A few parents said that they tried to maintain a positive perspective in life and adopted a 'get on with it' attitude. They added that this was very difficult to do. The majority of the parents said that they experienced mental health issues at some point in their lives. Low mood and depression were the two main ones that stood out from the data. Several parents had been prescribed antidepressants. A few were referred to counselling and psychotherapy to help them cope. Several mentioned an over-dependency on alcohol to cope with their situation. Attending parent groups and talking to parents with similar experiences was perhaps helpful. This aspect is explored in later sections of this chapter.

It unfolded in the study that both male and female parents had emotional issues. This was a highly significant finding of the study because, as demonstrated in the literature review, there is a dearth in the number of qualitative studies undertaken with male parents:

I thought I was suffering from depression and eventually I went to see a psychotherapist ... I had to go on antidepressants (Male parent 4, interview).

Now, latterly, the 3–5 years may be, on and off, I need a presence, drink too much, can't get away, can't have time to myself (Female parent 2, interview).

The study found that mental health issues appeared to manifest at different periods of the parents' lives. It is important to note that male parents in the study delayed or prolonged the acceptance of autism in their lives. This was particularly evident from the analysis of data for the couples in the study; male parents appeared to have a later onset of emotional and mental health problems than did their female counterparts.

I think I was offered some help, counselling, but never took it. I think at the time. I was kind of away from it first as a father, probably later when J showed us, she was taking so much interest (Male parent 2, interview).

I actually thought it's really very tough. It was really very tough I think after A specifically, I was depressed. My husband was depressed after E, for a while he went through depression and so and ... I had to get involved before with these professionals (Female parent 5, interview).

It became apparent from the data that parenting a child with autism had had an adverse effect on the emotional health of the parents. In their studies, Bromley et al. (2004) and Hamlyn-Wright et al. (2007) discuss parents of children with ASD exhibiting psychological distress, depression and anxiety. Compared with parents of children with other disabilities or of typically developing children, parents of children with ASD exhibit higher levels of stress (Baker et al., 2003; Belchic, 1996), anxiety (Baxter et al., 2000; Hastings & Brown, 2002) and depression (Feldman et al., 2007; Olsson & Hwang, 2002; Phetrasuwan, 2003; Singer, 2006). Although the resilience

and the spirit to carry on caring for their child with autism was evident in this study, emotional issues were a qualifier to understand how autism infringed on parents' sense of wellbeing and happiness.

8.2.3 Relationship Issues

One of the repeated notations in my field notes was that the research interview did not naturally flow into the discussion around relationships; however, parents were willing to share their perspectives when asked about this. It made me think that the parents were either so consumed in the world of autism that they failed to notice whether autism was infringing on their relationships, or that they had acknowledged its effect but did not talk about it until prompted.

Both male and female parents confirmed that parenting their child with autism had inadvertently created strains in their marriage or couple relationship. Three parents said that they eventually had to split up with their partners. The study also noted that after separation, the child with autism continued to live with the female parent. The absence of single male parents in the study is notable because no specific criteria were established to recruit or exclude single parents of either gender:

So, it does affect everything, autism, it really does and that's probably how we split up (Female parent 8, interview).

All parents, irrespective of gender, expressed their frustration and disappointment about not getting adequate couple time. The commitment of time required to care for their child with autism took precedence over the time they could set apart for their partners:

And we didn't have husband and wife time at all. It was like, I have done my bit, it's your turn, you do your bit, it's my turn. There is no time between us. It definitely affects the marriage life because we didn't have the time for each other (Female parent 3, interview).

I think you probably don't get as much time with each other, you know, unencumbered time with each other as you would do otherwise (Male parent 1, interview).

Few parents in the study managed to make time for themselves and mentioned that the quality of the time spent together was also affected. They said that even when they were together they would prefer to have no conversation with each other because of exhaustion or worry and anxiety about their child:

If we were to go away on our own, it probably happened about three times in the last 15 years. And then, when it does happen, it is for quite a short time period, a couple of nights if we are lucky. And, we are constantly concerned that everything is going to be ok (Male parent 1, interview).

One female parent spoke about how autism affected her sex life:

I am knackered and our sex life is pretty much non-existent (Female parent 2, interview).

Nineteen parents in the study identified themselves as living with their partner who was also the biological parent of the child with autism. The data suggested that although their relationships were dented and strained, autism had facilitated strengthening of the bond between them, with the commitment towards their partners reinforced. It was revealed that they realised the potential to work together as a team and support each other to deal with it. It motivated them towards sharing the responsibilities and challenges that came with caring for their child with autism:

I think that was kind of make or break and we decided, and ultimately we decided we weren't going to break ... I think because it just forced us really just to be more open with each other, just as now (Male parent 4, interview).

It is going to sort of bring you closer together because we have both got this thing that we have to do together (Male parent 1, interview).

The three single parents in the study identified that autism had a significant contribution in their relationship breakdown:

I: Do you think it was autism that resulted in you and your husband being separated?

Female parent 11: That's true because sometimes when you talk to him, you'll hear that coming out ya.

Inadequate couple time and strain in the relationship not only affected the quality of the relationship they had, but also prevented the individual from enjoying the relationship's full potential.

8.2.4 Summary

The North American Nursing Diagnosis Association (2001) defines fatigue as an enduring sense of physical and mental exhaustion not easily relieved by rest; in contrast to tiredness, which is alleviated by rest. While female parents in the study were found to take the lead role in caring for the child (managing behaviours, sleep, routines and so on), the study also found a small group of male parents taking a fair share of the direct caregiving responsibilities. This study has established the high caregiving demands and challenges associated with caring for a child with autism, leading to both male and female parents experiencing fatigue. This has been reported in other qualitative studies of parents of children with ASD and other disabilities (Benderix et al., 2006; Vicker, 2004).

High caregiving demands have also been linked to other wellbeing difficulties including depression, anxiety and stress (Ward & Giallo, 2008). While this was further acknowledged in this study, what made it particularly significant was that the finding could be extended to include male parents; the emotional wellbeing of fathers has been given less consideration in the literature (Davis & Carter, 2008). Further, male parents had a late onset of emotional wellbeing issues because of a delayed acceptance of autism in comparison with their female counterparts.

Relationship issues were also identified in the study, with couples highlighting the lack of couple time. However, with the exception of three parents, all spoke about autism playing a bridging role in strengthening their couple relationship.

So what does the above discussion suggest? The parents had a sense of discontent about their lives and this was amplified by reflecting on how their life could have been if autism was not part of it:

But definitely my life would have been completely different if S was normal. It's a horrible thing to say (Female parent 4, interview).

Parents openly acknowledged that they experienced a deteriorating QOL by highlighting the need for 'me time' and flagging emotional and relationship issues. In short, autism infringed on the sense of contentment they had about their life.

8.3 Restricts Participation

The definition of participation in the context of this study emerged from the specific challenges parents identified in their desire to participate in the different areas they considered important in their life. Analysis of the data consolidated three main areas in which the parents' wish to participate actively was restricted by autism. This included restriction on family participation (coded as 'family time'), vocational participation (coded as 'employment') and social participation (coded as 'social life').

8.3.1 Family Time

The study reinforced that caring for a child with autism is very time consuming and intense. To begin with, it affects the quantity and quality of time parents can commit to spending together as a family. They expressed disappointment in this regard:

That's typical and whenever we're going to the shops and when we are going to do some shopping you've got to make sure one of us has got to be there so we can't just go in the shops together, also one of us has to stay unless somebody else is looking after him and we don't tend to call people for that. We tend to keep them in reserve for the bad times we need them. So, we don't get to do the things together very much (Male parent 8, interview).

Because I have to take J away and we couldn't go somewhere together because it would just be too much for J or A (Female parent 7, interview; J and A are siblings).

This study found that it was very difficult for parents to take their attention off their child with autism because of their constant worry about the child's safety and wellbeing. Hence, in realistic terms, the study found that even when the family as a unit decided to do something together (such as go for a walk or watch a movie at home), one or other of the parents was in a constant 'state of high alert' supervising the child with autism. This anxiety and worry outweighed the pleasure of spending the time together as a unit. It also affected the time parent(s) could spend together with the other sibling. In other words, quality time spent together was fragmented:

You can't relax in an activity because you have to 24/7 all the time check on his safety needs and toileting etc. It appears to be the number one priority when you are out or even when you are in because the place could be flooded or it could be burnt (Male parent 2, interview).

Parents expressed a desire to enjoy their child(ren) together as a couple but it emerged from the study that parents usually would take turns to be with their child(ren) to give each other a break. This suggested that they were more likely to spend individual time with their child(ren) rather than as a couple. This would also make the family experience fragmented:

We would be going out not just for dinner or for a picture or whatever, to a bicycle run down on the beach. Whenever we are out, somebody has to be on C's case or with C 24/7. And you are all in the same place but you are not together per se; my attention is on C or G's attention is on C, or J and E or G and E (Female parent 2, interview; J and G are the parents; C and E are siblings).

It also emerged from the study that frequent appointments, visits from professionals, support organisations, friends and family members offering support was an inevitable reality in the household of a child with autism. However, many parents in the study expressed their wish to have dedicated time for themselves as a family with no visitors or visits. However, they also

realised that this was not always practical or possible when they have a child with autism, and it contributed towards making their unit fragmented:

I suppose the nuclear family, like two kids, two adults doesn't happen as much as we would like it to happen (Male parent 2, interview).

Finally, it was not uncommon in the data to note different members in the unit attending social activities or events separately because of a lack of alternative care options available. This inevitably fragmented their functioning as a unit as they really had no other option:

But then you are designated to go to this family party, but there is nobody, so H will go to half, I will go to half, it's not going together, you manage (Female parent 1, interview).

Both male and female parents confirmed that autism affected both the quality and quantity of family time. It had been a 'fragmented experience' that restricted their aspiration to have dedicated family time. This study also noted some gender differences in this area.

Male parents in the study mentioned that the child's need for strict adherence to routines restricted the spontaneity with which an activity could be undertaken. The behavioural reaction of the child would also have to be pre-empted to minimise the associated stress and anxiety not only for the child, but also for the parents. This, in effect, not only restricted the choice of activity they did together but also affected the family's lifestyle:

I suppose it's a fact that they are both quite limited in their interests and have set routines, so we can't start spontaneously. You just can't wake up in the morning ... well you can but need to prepare a lot in advance. You can't just suddenly say it's a nice afternoon let's go off to the beach. So you sort of have to get lots of advance notice or they get very anxious (Male parent 5, interview).

It was restricted, totally restricted your lifestyle and it restricted what you could do and where you could go. So I always feel unable do the things with E that I have done with D the older one. So there are places I just couldn't take him and I wanted to take him and it was too difficult because he

would have a tantrum but we tried. I mean that was ... it was trial and error (Male parent 9, interview).

Yet another aspect of family time that was important to parents of both genders was the quality of the time they got to spend with their other child(ren). Parents described the struggle to balance the attention and focus between the child with autism and their sibling(s). It unfolded that parents often felt sad and guilty about their inability to commit as much time and energy as they would like for their neuro-typical child. It appeared that most often the needs of the child with autism took precedence and the sibling felt left out or taken for granted:

That has been really hard as well, trying to find that balance. For A, it's difficult, because she has got a brother like B, she can't relate to him, doesn't want anything to do with him and from her perspective he gets everything that he wants (Female parent 2, interview).

I mean, one thinks I suppose, there is a bit of a risk when you have a disabled child that too much of the parent's energy can be focused on that, and we occasionally worry that you know that is at the expense of the other child (Male parent 1, interview).

Family time was also affected because of sibling(s) being expected to 'step up their act', to take responsibility for their brother or sister with autism from a very early age. This also affected the quality of family experience for the parents and the siblings:

Ever since he has been quite small, he always had to be on hand to sort of help out and try for example. he still does it, you know she quite often runs away in a shop or something and do a runner. He had to do a lot of things that we do. He suffers from the fact that he doesn't have a normal sibling ... He in a way has lost out on an entirely normal family experience (Male parent 1, interview).

There were also parental accounts of the sibling(s) having a tough time in their school or similar environment because they had a brother or sister who had autism. It was apparent from the data that the siblings' experiences had a flavour of isolation and restriction. However, parents also commented that the experience had helped their son or daughter to grow up as more

grounded and mature individuals. They were perhaps more aware of the needs of vulnerable people and were able to demonstrate empathy and respect for children with disability:

It will make him a sort of stronger and rounded person ... so it's not an entirely negative experience for him ... I think he is probably much more aware about vulnerable and disabled people (Male parent 1, interview).

He does take a hard time at school from other people in the school who would be that you have an autistic brother and still give him a hard time about that (Male parent 8, interview).

8.3.2 Employment

All parents who participated in the study were working in a full- or part-time capacity, or had been employed at some point in their lives. It was not surprising to note explicit gender differences in this area.

This study found that parenting a child with autism affected the careers/jobs of the child's parents. It appeared to be a very common scenario for the parents to receive calls at their workplace from the child's nursery, childcare provider or school because they were struggling to cope with the child. They also had to make arrangements to attend meetings and appointments related to their child. Although parents reported their employers to be reasonable and understanding, the study found that parents recognised themselves to be in a situation that was unsustainable. The study also found evidence to suggest that the demands of caring were exhausting and draining and parents struggled to be productive in their workplace:

Well obviously you have got a lot more meetings when you have a kid with autism, so, I work part time (Female parent 2, interview).

I went back to work when she was born and then I got ... it was like too much going full time and then coming and looking after her. So, I went part time at night ... but she was just becoming too much for my mum and plus the way it was, I wasn't feeling at ease leaving her, do you know what I mean? (Female parent 8, interview).

It emerged from the study that female parents were the first port-of-call for responding to the unforeseen emergencies related to the child's needs. It was noted that apart from the three female parents who worked part time, the rest of the female parents had to make a circumstantial choice of giving up their work to manage the caregiving demands of their child with autism:

*S's condition is part of the reason of me not working ...
(Female parent 4, interview).*

Obviously I was needed here more and definitely because as E was getting older and we were getting less and less out of him, I think myself I just couldn't concentrate at work anymore (Female parent 5, interview).

Among the 19 parents who identified as couples, it was reported that the male parent was the main, and mostly the sole, breadwinner in their family. Eight of the 10 male parents who took part in the study worked full time; one was looking for work; and the remaining parent was unemployed, explaining that he wanted to share with his wife the responsibilities of caring for his children with autism. Male parents were found to be anxious about the family's finances:

I: Did it have an impact on finances?

Well it has in a way that obviously when J was first born M went back to work. She kind of gave up on that really once they were diagnosed, because there's so much more work involved in looking after... (Male parent 5).

Yeah, well it does, my wife had to give up her career completely. She hasn't been able to go back to back to work, because she has to be available to look after her daughter ... I am working full time but we are dependent on one income ... But financially, we haven't had the benefit of her salary (Male parent 1, interview).

Male parents highlighted that autism restricted their employment options and working hours. Exploring other avenues for career progression or growth prospects across geographical locations was limited. Parents negotiated their work pattern to share some responsibility with their partners to care for their child with autism, thereby restricting the time they could commit to work:

If I wanted to take up a job in London or New York, which I could do, I have to think twice about that (Male parent 1, interview).

Because they want people to work all kinds of hours of night, weekends and that kind of thing. But I haven't been kind of a fit in the abilities do that, because of the work that goes into looking after children (Male parent 4, interview).

I could not give much time to my work (Male parent 3, interview).

Female parents shared their resentment about not being able to work and being a contributing member of their household and of society. They expressed their disappointment in having to give up their career goals and the dissatisfaction of living on benefits:

I did, I want to be head-teacher, that was my ambition and I feel I had that really thwarted. That is my biggest gripe. I do now claim carers' allowance ... I can do little bits, but it is very difficult to say, you cannot get a job where you do two hours there, two hours there. That doesn't exist ... but at the same time I had to confront Q's career so I had to sit back and I have resented you know ... his life sometimes can be too colourful and too interesting and I am just sitting here, even though I am trying to make it colourful and I can share a bit of that (Female parent 1, interview).

Oh it has, because I am on benefits now, and I hate the thought of benefits because I would rather be working (Female parent 4, interview).

Last, the study also found that there were no incentives for both parents of a child with disability to work full time as this affected their tax credits and other financial entitlements:

I work part time, work 24 hours per week, before if I didn't work 24 hours per week, G and I collectively would lose the child tax credits and tax credits, and at that point it was £690 which we couldn't afford to lose (Female parent 2, interview).

8.3.3 Social Life

The data shed light on the fact that the parents of child(ren) with autism did not have as many opportunities as they would like to enjoy a social life to

which they aspire. Their participation in social activities/interactions was restricted because of autism, leaving them feeling isolated:

I think we would just like to be able to get out more and have a bit of a social life for ourselves, either individually or as a couple (Male parent 4, interview).

Basically, being a human being, most important thing is social interaction with other people. That is affected (Male parent 3, interview).

Parents in the study were of the view that having a child with autism once again restricted the flexibility, the time and the energy they had available to commit to socialising with other people. The study found that the caregiving aspects and the parenting responsibilities associated with a child with autism were so overwhelming that they struggled to balance them with a good social life. The increased difficulties of managing their child out of the home environment made them increasingly reluctant to go to restaurants or to a movie. It immediately put a brake on their social life:

That just is very, very hard to sort out and again, also we just like to be able to do things with the children. I mean it's very hard to take them out to a restaurant because J for example is very, very restless and he comes to nothing. So it's very hard for them to sit down quietly for a meal without drawing attention to themselves (Male parent 4, interview).

The child's sensory issues, for example their inability to cope in crowded places, made parents worry about the risks and safety parameters, leaving them anxious about the uncontrollable and unpredictable nature of the immediate environment when they were away from the home. Parents spoke about making conscious choices to avoid specific social events like barbecues or birthday parties because of the same issues:

We have done to a point, but we kind of pick and choose where we go. Because, if it is an uncontrolled area, it's a complete no, we are not taking a chance ... But it is all planning again, plan by plan, risk assess, health and safety, that is all what you are doing before anything happens (Male parent 2, interview).

Male parents identified going on holidays as an issue. Holidays were not a normal or natural occurrence in these autism households. It was not unusual in the study to hear parents say that they had never been on a holiday. The inflexibility of routines associated with autism was a major stumbling block, along with the unpredictable environment and the sensory and behavioural issues that a holiday may trigger. Parents were put off the idea of going for holidays because they said that they would be constantly anxious about how their child would cope and how they themselves would manage. With few exceptions, parents in the study were of the view that their child(ren) with autism coped best in the home environment, hence they were not keen to 'rock the boat'. The very few who attempted holidays either had an unpleasant experience or had done lot of planning and preparation to prevent the occurrence of any major hiccups. A male parent developed a book for his son detailing more or less everything that would happen during the holiday. However, it transpired that a slight change in plan from what was detailed in the book was upsetting for his son. These parents, like the very few who went on holidays, said they could not relax, but could at least attempt to make the best of it:

I mean a few years ago we went to Germany for a couple of weeks and I actually sort of designed some book for the children to explain what we were going to do, and the fact we were going on a plane and going to hire a car and that kind of thing. That worked out quite well, but it's still quite difficult because here we go off somewhere in the car, drive somewhere else two hours away. So we tell J we are going out, we are going somewhere, for a day out. What happens we drove off for 2 hours and we parked and we went to have a coffee in a café and J felt that was the outing and said he wanted to go straight back to the car and go home again (Male parent 4, interview).

Inviting other people to their homes was also not a frequent option:

I never go, I hardly ever go out, even socialising bringing friends up, I mean it's alright at the start, but at ten o'clock then I've got to say, well, we can't make any noise, because if at ten o'clock the least bit of noise and she's up, so it's crap, it really is (Female parent 9, interview).

On a positive front, networking with other parents in similar circumstances (those having a child with disability) was seen as a favourable outcome for the parents in the study:

You do make some good and close friendships. We have got another family that have got a child is lot disabled than C. That was the thing we have in common. We discovered that we had other things in common (Male parent 1, interview).

8.3.4 Summary

Roberts and Lawton (2001) and Heaton et al. (2006) summarise that the extra care demands of caring for a child with a disability affected the time available for other family activities. This study complemented findings of the aforementioned studies; it spelled out the specific context of autism and gender differences; and added the dimension of siblings to family time, identifying that they were restricted in having as much quality time as they would like to have with their parents.

It emerged from the data that careers were yet another aspect that was important for the parents' QOL experience. While female parents resented their inability to be an active participant in their line of work, male parents experienced that autism restricted their level of participation at work by affecting their working hours and avenues for career growth. The data also reinforced the role stereotyping reported in the literature, where the female parents took the lead role of caring for their child and the male parents resorted to working and ensuring the financial stability of the family.

Townsley et al. (2004) identify parental isolation in their study related to disabilities. In addition to identifying gender issues related to restrictive social participation, the current study explained the autism context related to this. However, it also identified 'networking' with parents of other children with disabilities as a positive outcome in their social participation.

In short, parents' QOL experience was restricted because of their limited capacity to participate in the family functioning, to contribute to work and to enjoy a regular and uninterrupted social life.

8.4 Limited Opportunities

Opportunities were contextualised in this study by those areas the parents identified as contributing to a restrictive QOL experience by their absence, non-existence or limited access. A rather controversial view of universal services like health and education was implicit in the parental accounts that offered limited opportunities with the understanding and management of autism. Having limited or sporadic access to help from family or friends and lack of leisure activities for children with autism also limited the parents' potential to have the QOL to which they aspired.

8.4.1 Universal Services

The PHIS (2001) recommended the development of guidelines to improve the assessment and management of ASD. Although a comparison of parental experience pre- and post-introduction of these guidelines is beyond the scope of the study, this recommendation for improvement would synchronise with the lack of confidence expressed by parents in the competence of health professionals. Parents did not appear to receive the direction and collaborative assistance they expected from health professionals to deal with their child's autism. They felt shunted around and dismissed by professionals, which made them frustrated and angry. Professionals also failed to instil confidence in the parents regarding their expertise with autism:

So our quality of life hugely reduced, because we didn't know what to do with her and the very people we were ... speech and language therapist ... they didn't know what to do with her ... The other medical people, they haven't got a clue, how to communicate with C ... I would like someone to take note of me as a parent, when I had all these concerns ... I hoped we were directed to somebody who could enable her communication from the age of 2. Instead they said she

is so unintelligent, she won't be able to do this, this and this ... my conclusion is yes she wouldn't be able to do that because nobody was prepared to do anything to enable her to do that (Female parent 1, interview).

There was evidence in the study that parents resorted to quasi-intervention experiments, especially with the child's diet, in the hope of making their child feel better. These interventions were self-initiated by parents based on their own research on autism. The data did not suggest that such interventions were endorsed by the health services. Despite this and the added financial strain caused by some of these interventions, parents still considered them worth a try. This highlights trust issues with health services:

We had to pay for everything, mostly clothes, diet because he had to have gluten and casein-free diet, egg free, nut free and it's all the same stuff. Gluten and casein-free are expensive. I remember that he used to get gluten-free bread and it was £3.99 a loaf (Male parent 2, interview).

We also took him to America for two weeks to do an intensive programme that cost us £10,000 to do that ... and I think it's because you work in now sort of an environment where there's no distractions and what you're doing is you're sort of ... you're joining him, you're echoing what he's saying, and we don't get a lot of words out of him, but they want you keep him in the house, not to take him out very much and we didn't agree with that ... So we stopped that after a couple of years (Female parent 7, interview).

Given the severe communication problems associated with autism (as described in Chapter 4), parents believed that any intervention had to be intensive. This was not reciprocated by health services:

It was a kind of six-week block of S&L therapy that we got, to be perfectly honest was a total waste of time, again, it was I think half an hour once a week for a kid that has got severe communication problems (Female parent 2, interview).

The experience of getting a diagnosis was frustrating for the parents. This was more relevant to study local authority 1 and study local authority 2 than study local authority 3 because of considerably higher waiting times:

And then we were on a waiting list. It was all waiting, hanging about and then eventually when the diagnosis, I

mean eventually he was put, in because it was getting quite close to the time when he was starting school. He was put in a kind of a group diagnosis thing (Male parent 4, interview).

Parents also held a similar view that the education services were not adequately equipped to deal with autism. Seven parents in the study spoke about home schooling at various levels (from fully home schooled to a combination of home schooling and special needs schooling) and advocated applied behaviour analysis (ABA) and verbal behaviour (VB) therapy to be considered in educating children with autism:

We have found a way of applied behaviour and descriptive trial training was a way to talk to her and that was just an open door to teach her literally anything ... The primary school had nothing to do with the teacher and she said I don't know what she is doing here, she upsets other children, she makes people cry, she makes us cry and her special needs teacher, the school said she is frightened of her. I had to hand my child every day to someone who told me I am frightened of her and I don't know what to do for her. And that is my only respite (Female parent 1, interview).

8.4.2 Informal Support

According to Turnbull et al. (2006, p. 213), 'Social support refers to a source of comfort found within group and individual relationships'. Within this realm of social support, Benson (2006) finds that informal parent support (e.g., help from family and friends) significantly decreases depression among parents of children with ASD. Social and emotional supports are found to reduce parents' stress and improve their wellbeing (Crnic & Low, 2002; Siklos & Kerns, 2006; Turnbull et al., 2006).

However, the findings in this study did not identify a substantial level of help from family and friends for the participant parents. Three male and three female parents acknowledged receiving some level of support from their extended family or friends, whether it be going on a holiday together or offering respite overnight:

Oh yeah, absolutely ... fantastic, my mum and dad they have always been there for us (Female parent 2, interview).

We spent with M's family as well. This year we went to France. We had a week just for ourselves in the campsite and we had a week in a house with her parents and her sister's family and they've got two children and they get along quite well with our boys. So that worked out quite well (Male parent 4, interview).

However, because of the specific challenges of autism (e.g., behavioural issues, sensory issues and so on), extended family or friends were only able to offer limited support:

She did not mind dad staying with us, But if I was making dinner, and S is having tantrums upstairs, my dad will say, I will deal with it and dad will go upstairs and deal with it. But S did not like that, he wanted me to deal with it ... so when he come down, it was like throwing himself down on the floor and saying why are you letting granddad trying calm me down. That is your job. So once I took over, he calmed down (Female parent 4, interview).

Family support is limited. You know, for example if we wanted to go away somewhere, parents want to go away and leave the kids with somebody else, that is extremely difficult to do and we hardly ever do that because of that. Because, there are probably only one or two people that could look after C (Male parent 2, interview).

Given the nature of challenges posed by autism, any help for parents should be ongoing and consistent over a period. Data from the study did not indicate that this kind of help was available for the parents to access from their immediate family or friends. The hidden nature of this disability (children looking normal) may have made the explanation of their child's challenges even more difficult.

8.4.3 Activity Options

The sociologist Michael Oliver (1996a, p. 35), one of the pioneers of the social model of disability, states 'disability is wholly and exclusively social'. Barnes (1991, p. 2) explains this further by defining disability as 'the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers'. This study

found that community attitudes restricted the options that parents had to engage their child in various activities, thereby limiting their opportunities.

Parents in the study spoke about being embarrassed by their child's behaviour in public. Although they were aware that many of these behaviours were involuntary (flapping, noises), they were saddened to see their child do this. It inevitably attracted people's attention and responses. This study found that parents did a lot of thinking and planning prior to making a decision to take their child to different places. They were anxious and worried that their child's behaviour may 'spoil it for other people'. This would inadvertently restrict where they could take their child. It emerged from the study that many parents were deeply affected by the reactions and responses invited by their child's behaviour. It unfolded from the data that reactions from the public could vary from odd looks and stares to angry retaliations. It was also disheartening for parents to see that their child did not have the awareness of understanding to gauge reactions to their behaviours. They more or less remained unaffected, which was quite a sad moment for parents to witness:

We tend not to do that because they do spoil it for other people, quite thoughtful that way, because of noise and age and stuff like that. I know it is a pain. I know, the society for all this should be changing and should be quite tolerant, but they are not (Male parent 2, interview).

I feel for A although I don't think he has got any awareness, it doesn't bother him or it doesn't appear to bother him, if people were saying stuff, he wouldn't understand what they were saying ... I would like to say it doesn't bother me, I suppose at the end of the day it probably does (Female parent 2, interview).

There was a 'sense of helplessness' among the parents towards the attitude of the community. Most parents felt that there was not a lot that they could do to avert the attention and reactions from the community. Parents would clearly like to see a more tolerant and inclusive society for their child:

They just stare at him because of the way he acts because he shouts like as in, you know, just his actions, he's got this floppy things that he flaps at his feet all the time and cause a look you can see them looking at him. So he definitely draws

attention. However, I'm so used to it now (Male parent 8, interview).

My wife cleaned up the thing, the people in the supermarket rushed off to clean up and this woman still going ... erh, erh, erh ... very visibly still showing her displeasure at it and my wife ... She said her life is difficult enough, she has got autism, her life is difficult enough without somebody like you behaving like that. That is a particularly bad incident ... That was a pretty upsetting incident. But that is rare, it doesn't happen very often but it doesn't have to happen very often to be upsetting (Male parent 1, interview).

The data revealed that—compared with those with a physical or learning disability that is perhaps more easily identified by its physical presentation—autism is hidden. Hence, there is an expectation for children with autism to comply with the unwritten rules of socially acceptable behaviour. Not surprisingly, several parents were of the view that more education and awareness about autism would be helpful:

Everybody who knew what her problem was, because she looks absolutely normal. This was the problem. As she has grown older, she has begun to look disabled in that she can stand out from the crowd with her behaviour not her appearance (Female parent 1, interview).

Because they just see our child as a normal kid and you have to blend in. Nobody has understanding. Like I said, with a Down syndrome child or a physical disabled child, they treat them differently. But if I am with an autistic child, outside they look normal, but inside what their brain functions, they flap and they do all the other stuff (Female parent 3, interview).

One or two parents had a lot of praise for their local shopkeeper or swimming pool attendant who in their view had gone beyond the call of duty to accommodate their child:

Well, we go a lot to the shop ... the guy is great; S walks in and they have always got sweeties in the counter and I think S thinks they are for him and S goes in and take one and he goes round the shop, gets his shopping and take another one and I say they are not for you. The guy he is brilliant, he is really good with S (Female parent4, interview).

The study found that the attitude of the community had not been particularly inclusive and tolerant towards children with autism. Parents said that they would eventually develop a 'thick skin'. It also had an effect on the choice of places they went to and the frequency of visits to places such as restaurant or churches.

8.4.4 Summary

This section examined how the parents' QOL experiences were restricted because of limited opportunities manifested by inadequate universal services, sporadic family support and negligent community attitudes, which together limited the opportunities parents had for managing the strains and challenges of autism effectively.

8.5 Conclusion

The following accounts summarise the emerging findings of this chapter:

But a normal child as they grow up they become independent day by day. But in this case, things don't change. Right from the start, till now, they are dependant. So there is extra hard work, apart from our daily routine jobs, we have to put extra effort, extra time. So it's a burden on our lives (Male parent 3, interview).

So, quality of life, it has been, our life is unequal, unequal to the most basic things ... we joined a couple of autism projects which analysed her bowels which no medical provision had thought to even try. Some children have chronic diarrhoea, that is how it is, doesn't matter nobody else in the household. Just live with it. And we thought, oh no, why should she live with stomach pains and all the rest of it. Then, the quality is, we have to find it ourselves, I think all autistic parents will tell you, you have to learn to be a fighter, not to take no, to keep pushing, to keep pushing, there is a limit to how far you can push, because quite frankly they can't provide what you are looking for and can't/won't. So, quality is get her an education, get her healthcare, access to shops, and anywhere it has been a problem (Female parent 1, interview).

Figure 8 provides a pictorial representation of the overarching category, subcategory (property) and codes (dimensions) that emerged using the axial coding process in grounded theory analysis.

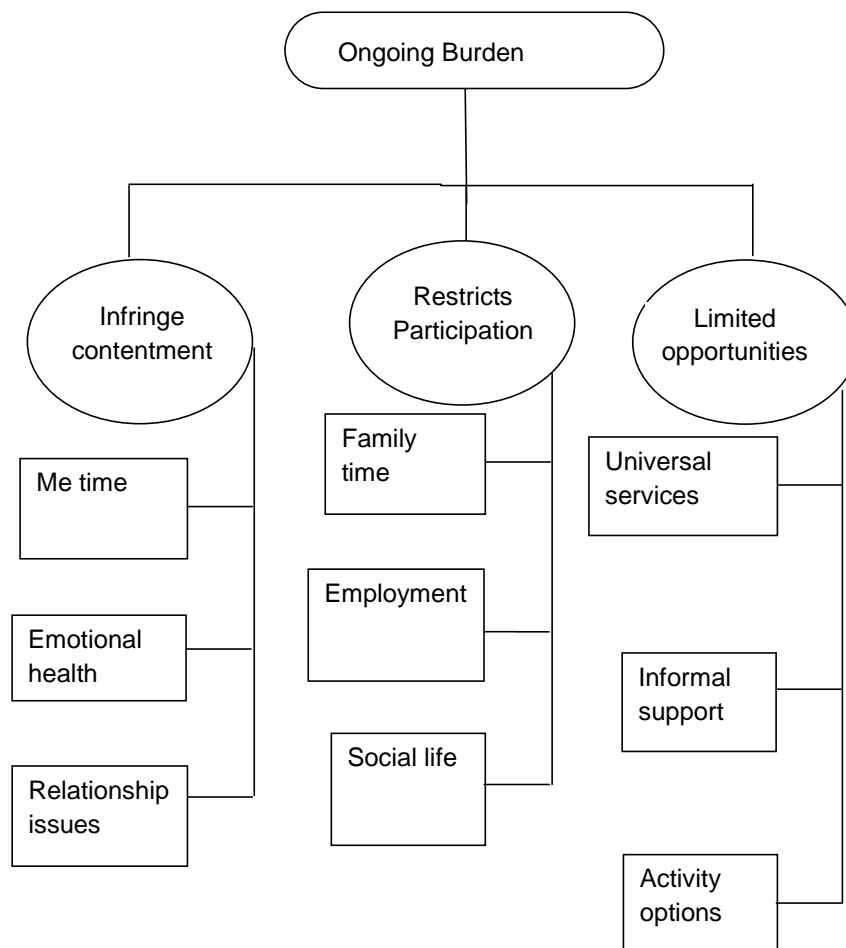


Figure 8: Properties and Dimensions of 'Ongoing burden'

This chapter pulled together the data that offered parents' perspectives of their QOL experiences. Parents identified specific areas in their lives that were affected by autism. By ruling out the use of established instruments and scales, this study aims to capture the parents' definition of their QOL experience and what they consider important to be used as indicators to

describe their wellbeing. Parents of both genders in this study described living with a child with autism as a constant burden, which led to the emergence of the overarching category 'ongoing burden', which had three properties (subcategories). The emerging gender differences in each area were captured in the discussions above.

The analysis began by exploring what were some of the personal aspects of parents' lives that were affected by autism. Parents expressed a sense of discontent when identifying these specific areas. Coded as 'infringe contentment', the parents included lack of time for rest and self-care (coded as 'me time'), mental health issues (coded as 'emotional health') and issues with their partner/spouse (coded as 'relationship issues') as the three main areas that made them feel unhappy.

The second property (subcategory) 'restricts participation' explained in further detail what parents saw as some of the areas of which they aspired to be an active part but could not, because of the effect of autism. These findings were contextualised in the following dimensions: (a) family time, (b) employment and (c) social life.

'Limited opportunities' was the third and final property (subcategory), which explained that the burden of caring for a child with autism was amplified by inadequate universal services (coded as 'universal services'), limited support from immediate family and friends (coded as 'informal support') and unfavourable community attitudes closing off social options for the child and parent (coded as 'activity options'). Ongoing burden is the second category that qualifies the oppressive experience as outlined in chapter 6. The nature and extend of the oppressive experience characterised by 'ongoing burden' is further discussed in chapter 11.

Chapter 9: Findings Part 3—Limited Help: Inadequate Interventions, Disempowering and Non-engaging

9.1 Introduction

The previous two chapters examined the parents' definition of their QOL experience. It summarised that parents described their world of autism as the new normal and their experience with the child with autism as an ongoing burden. The study found the challenges that autism brings to parents' lives had a compounded effect on other areas including health, job, relationships and finances; areas identified as important in their QOL experience. It is emerging from the study that parents are looking for help where possible; the informal circle of help from their extended family, friends, neighbours and local community was rather limited. Where was the support from universal services like health and education? It is relevant at this juncture to ask; What help does the state offer?

This chapter aims to capture the similarities and differences in the perceptions of parent participants versus social workers/operational managers regarding the services offered from social work and their impact on the quality-of-life experiences of the parent respondents. While the main group of parent respondents in this study received some form of service from social work, a small group of parents did not receive any service from social work (see chapter 5 on research methodology for more details). A concerted effort was made to ensure that the parents' views were given due importance throughout the analysis.

The grounded theory analysis suggested that parents who received social work services reluctantly acknowledged that the services did assist to improve their QOL experience; however, they were quick to elaborate on why their experience with social work was far from satisfactory. The study found that female parents were the primary point of contact for social work within their family unit. However, parents of both gender appeared to hold similar views on the kind of help they needed; for example, respite or break.

They did not appear to express a confident and optimistic view of the help they received from social work. All of the parents who received some form of social work service expressed their desire to access the social work service in anticipation that it may have improved their QOL experience.

However, social workers and operational managers were of the view that there was scope to expand the services on offer for children with autism and their families. In essence, both the parent respondents and the social workers/operational managers implied that there was scope for improvement of the services offered from social work. Hence emerged the overarching category 'limited help', which qualified the perceptions of current service provision and its implications for the QOL experience of the parents.

This category had the following subcategories (properties). The subcategory coded as 'inadequate interventions' captured the views of the parents and social workers/operational managers around help from social work and some of the challenges and difficulties associated with getting/facilitating this help. The analysis further captured specific areas identified by parents and social workers/operational managers that made their interaction with each other rather strained, coded as 'non-engaging'. The last part of the analysis focused on the sense of helplessness experienced by parents and social workers/operational managers while accessing or offering a service, coded as 'disempowering'.

Before I tackle each of the aforementioned subcategories in greater detail, I discuss the processes and procedures within the social work apparatus that led to service delivery in the three study local authorities. All three study local authorities had a specific social work team to cater to child(ren) with disabilities and their families. Two study local authorities had one team for children with disabilities and the other had three disability teams. It was beyond the scope of this study to focus on the intricate and exhaustive details of all processes. However, this section aimed to present a brief explanation of how a request for help (also known as referral) travelled through the social work apparatus of the three study local authorities.

9.2 The Journey of Help

In the grounded theory analysis, the journey of help can be put into perspective using two codes that emerged: referral (the request for help) and assessment process (the process that identified what help was useful for children with autism and their families). The dimensions of the code referral included source (Where did the referral come from?), point of contact (How was the referral initiated?) and criteria (thresholds for referral to be considered eligible for the social work teams). The code assessment process was qualified using the following three self-explanatory dimensions: pre-assessment, assessment and post-assessment.

9.2.1 Referrals

Referrals are requests for help (service) made to a local authority social work. Knowing the source of referrals, where the referrals were made (point of contact) and the criteria used by the disability teams in the three study local authorities to accept these referrals will provide a clearer picture of referrals.

9.2.1.1 Source

The three study local authorities were open to referrals from any source; however, they received referrals predominantly from universal services like health, education or families making self-referrals for their child with disability (autism in the context of this study):

Health professionals make referral ... referrals coming from other local authority workers, from education professionals, health visitors, other local authority professionals if the young person is moving here and they have had a care package in place in other local authority and they want to transfer the care package, so have a reassessment done (Social worker 3, interview).

However, we get a lot of self-referrals as well from ... not children, I mean from families (Social worker 9, interview).

9.2.1.2 Point of Contact

The three study local authority had different mechanisms in place or points of contact for managing referrals. In study local authority 1, all new referrals (children with disability and the family who were not known previously to the disability social work team) were streamlined to a central call centre. An initial screening was done at this centre to determine the appropriateness of the referral to the central practice team for children with disabilities. If the team had known the child or family prior to referral, the family may be contacted directly:

New referrals come through ABC (anonymised). Families that are already known to us, professionals or the families obviously can contact us directly (Social worker 2, interview).

Study local authority 2 had recently introduced a referral form that families were expected to complete and sign to ensure the authority was aware of the referral. This was introduced to ensure more accurate information, rule out inappropriate referrals (e.g., referrals without consent) and prioritise referrals based on the information provided. However, none of the social workers in study local authority 2 spoke about using this referral form. It appeared that disability teams in each locality would take referrals over the phone and log them in the computer system to be dealt with:

We have a dedicated disability team and three areas across ... we have our own referral form. We ask agencies to provide and fill that out and that was just about because the quality of information we get was so sporadic and totally wrong addresses and all that kind of stuff. That was just about formalising it. We were getting a lot of inappropriate referrals, not always the family is aware that a referral been made (Operational manager 2, interview).

Mean for example sometimes GP [general practitioner] assesses, you may take a call from say maybe a GP or a family themselves, and we have to take the basic details and then what we would do is, add them into our database for initial assessment (Social worker 12, interview).

In study local authority local authority 3, the central disability team was the single point of contact for making referrals. Hence, all referrals were

managed through the duty system (where each member of the team was on call on a rotational basis):

Well we receive it, we'll do a duty system, we do receive referrals from health, from schools; there are actually probably quite a wide variety of referrals, they come from a variety of settings and quite often parents themselves maybe asking for an assessment of need (Social worker 7, interview).

9.2.1.3 Criteria

All three study local authorities considered the diagnosis of disability and the child's age as the two most important qualifiers for the referral to be considered for their disability teams. Study local authority 1 and 2 did not consider referrals with a diagnosis of ADHD unless the child had an additional diagnosis of a disability. Study local authority 1 made the criteria more stringent by not accepting referrals for children and young people who had a diagnosis of high-functioning autism unless they had another associated diagnosis:

So we're a children and families team specifically for children with a diagnosis of disability. To qualify that a little, we don't accept referrals for children and young people who just have a diagnosis of high-functioning autism, we don't work with children who have ADHD, although we do work with them if they have an additional diagnosis. The disability would need to be the main reason for referral (Social worker 4, interview).

With regard to the age of the child, the study found that the three study local authorities considered pre-birth to the age of 19 as an appropriate age range for the referrals to be considered by their respective disability teams for children and families with disability. There was a certain amount of flexibility for the teams to continue to work with the child even if the child had technically exceeded the upper age limit:

We worked from pre-birth to 19 ... As of yet the child does not need to have a certain IQ ... we work across disabilities ... However, we do not work with children who only have a diagnosis of ADHD (Social worker 9, interview).

Any children with disabilities from 0 to 16, although we have other young people up to age 19 (Social worker 8, interview).

The next section examines the assessment process.

9.2.2 Assessment Process

Under s 23–24 of the *Children (Scotland) Act 1995* the local authority has a duty, when asked, to assess the carers of and children/young people affected by disabilities to determine the needs of the child/young person (with autism in the context of this study) and the carers' (parents in the context of this study) ability to provide care for them.

Each of the three study local authorities had a framework in place with regard to undertaking an assessment. It emerged from the data that the framework encompassed three main stages: pre-assessment, assessment and post-assessment.

9.2.2.1 Pre-assessment

The team leaders of the disability teams across the three local authorities screened the referrals and allocated them to a worker for a screening visit. There was an expectation that the screening visit would be completed within two weeks of the referral reaching the team. It appeared that the purpose of the screening visit was to ascertain, after discussion with the child with autism and their family, whether an s 23 assessment was necessary for the child. To understand the circumstances of the child and the family during this visit, an initial assessment was expected to be completed. Assessment under s 23 of the *Children (Scotland) Act 1995*, commonly called a 'Section 23 assessment', was deemed necessary when it was identified that the child with autism and their family needed to access help through local authority social work. Help such as clubs, befriending (now called community support in study local authority 2) and sitter service, overnight short breaks or funding for specific support were a few of the main services considered resources by the three study local authorities. Both study local authority 1 and study local authority 3 had a two-week time frame in which to complete the initial visit.

There were insufficient data to ascertain whether these service standards were met:

Well we could have a screening appointment, would be done within two weeks, our standard routine (Social worker 4, interview).

so the duty worker will go out to visit with the family what the options are, what is available. We often give them a list of services that are available without social work involvement, things that they can just access themselves; charity things, clubs in the community, that sort of thing. At the same time, short assessment is carried out. It is to get an idea what is appropriate for the family (Social worker 1, interview),

and have to we take the basic details and then what we would do is, add them into our database for initial assessment. And then what would happen is a person will be allocated to go and do initial assessment (Social worker 12, interview).

9.2.2.2 Assessment

All three study local authorities had a waiting list to have a Section 23 assessment completed. Both study local authority 1 and 3 had a 12-week (three month) time frame in which to allocate a worker and undertake the assessment. Once allocated, the worker had another 12 weeks (three months) to complete a Section 23 assessment. Study local authority 2 had a similar process; however, there were insufficient data to indicate whether time frames were met:

We would go into the assessment and it'd be allocated to a worker or quite often it had to sit in some kind of waiting list because everybody's stretched, but once it is on your clipboard you'll get a name, you go and see the family, you'd speak to all the relevant agencies and you try to draw up, to get some kind of assessment (Social worker 10, interview).

The assessment should be allocated within six months and then it needs to be completed within three months. Those are standards that we kind of came up within the last couple of years (Social worker 4, interview).

So, there are time scales attached and that's where our service standards come in, yes and our service standard in

terms of, you know screening referrals within a couple of weeks and allocation within 8–12 weeks and then completion of assessment within 12 weeks. So, we do have certain standards and one of the things we're conscious of is that we haven't consistently met service standards due to the demands on the service (Operational manager 3, interview).

9.2.2.3 Post-assessment

Study local authority 1 had a priority scoring chart that scored different parts of the Section 23 assessment. The assessment required a certain minimum score to be considered by the allocation panel for accessing gated services. A waiting list was maintained to manage the demand against the resources available:

There is a bit of a gap between the thresholds for receiving social work visit and then getting an actual service, an actual kind of respite or outreach anything like that ... The scoring determines whether or not they can get the service ... In terms of waiting for a service that's really difficult to know because it's all based on scores, so someone with a really high score could just be given the next place. The next place might not become available for nine months, so that is another tension. Every minute all the units are filled and so... (Social worker 4, interview).

The study found that the remaining two study local authorities did not have a scoring system; however, the assessments would have to undergo the scrutiny of a panel for approval to access a service:

Then it would go back to the team manager with what you've recommended for that family and if that's applicable and if that service is applicable or not and then the team manager would look it up and either discuss it with panel (anonymised), which is a further group and further accessing more services (Social worker 6, interview).

but if it's felt that they needed support, then you want to do that further assessment that would then be the basis of what you take to the AAA (panel anonymised) (Social worker 12, interview).

These responses suggested that the entire process of assessment was intense and time consuming. There was no guarantee that a service would be provided for the child with autism and their families at the end of the

assessment process. This raised the question of whether the child with autism and their families were supported with the right services at the right time (GIRFEC, 2013).

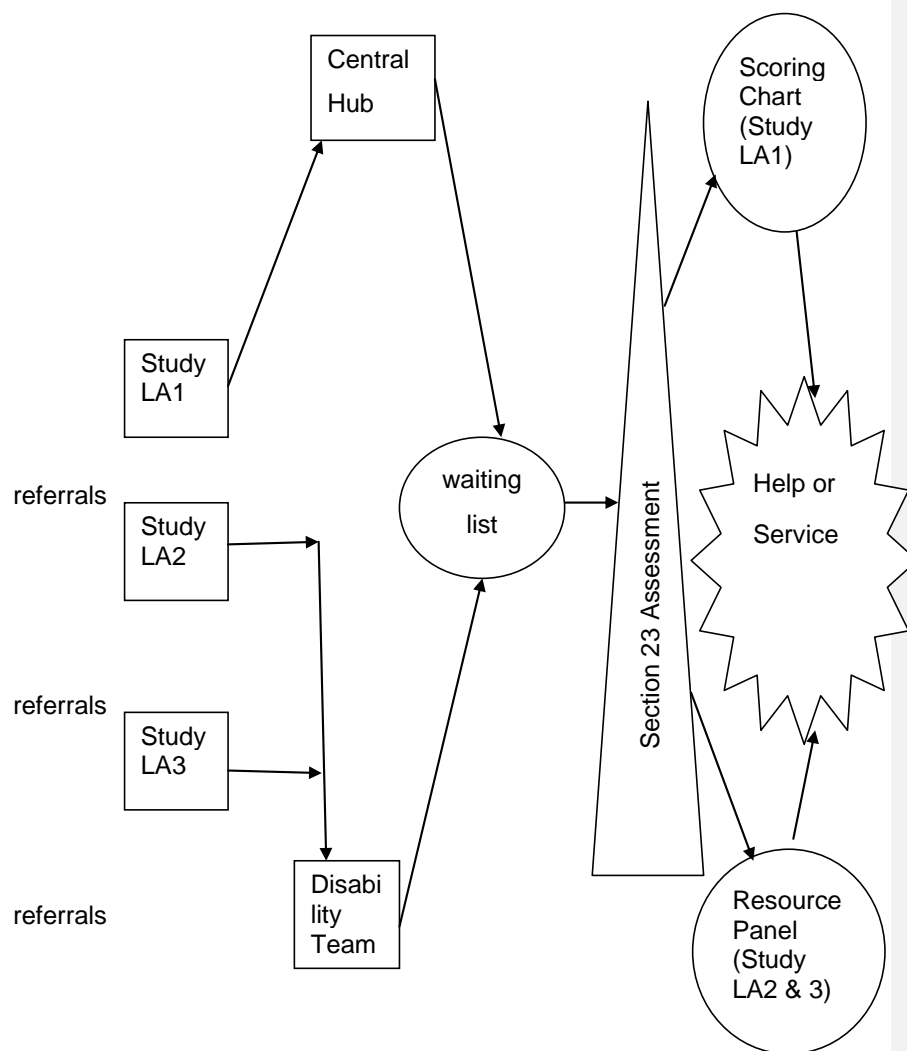


Figure 9: Journey of help

Having discussed how a request for help travels through the social work apparatus, in the following section I examine the help from social work in the

context of the QOL experiences of the parent respondents. I begin with the first subcategory 'inadequate interventions'.

9.3 Inadequate Interventions

The previous two chapters summarised the parents' experience of living with a child with autism as a burden, and this was echoed by the social workers and operational managers in this study.

'Always living under siege from their own child', was a very powerful phrase used by a social worker to summarise the effect of autism on the family. The study found that social workers/operational managers across the three study local authorities viewed the experience of parent(s) with a child with autism as difficult and challenging:

A lot our parents are very socially isolated because they are living in this bubble of their child's autism ... a few families have admitted that the stress of dealing with autism and the child has caused the relationship to break down ... they have been up all night with the child who doesn't sleep, so it would be difficult to go to work anyway. So they got the financial burden ... wider family support, aunts and uncles, a lot of them struggled to understand autism and a lot of them think the child is being naughty and it's your fault that they are being naughty ... children with autism, most of them need so much structure and routine, so they can't be flexible or spontaneous (Social worker 1, interview).

The social workers identified the concept of a normal family life as alien to children with autism and their families. They were of the view that autism was an overpowering experience that dominated the family unit. As identified in previous chapters, the autism more or less dictated the day-to-day functioning of the family in a rather restrictive way:

My feeling is that actually they have to adapt to a family life that isn't really conformed to anything that more or less looks like family life. I think it predominates all the experience of all the relationships and I think that probably trying ... some of them are trying to hold on to concept families and the

situation where the child can actually call the family life; that's my perception of them then. Actually, they're trying to hold something together; an ideal of something is probably almost impossible to do (Social worker 5, interview).

Although both respondent groups (parents and social workers/operational managers) agreed about the restrictive nature of autism, they had varying and at times contrasting views about the help (also termed as interventions in this analysis) from social work.

9.3.1 Real-time Help Versus Help on Offer

The study found that parents reported delays between social work being requested and actually received (does not receive help in real time). Parents argued that they often sought out help from social work long before hitting a crisis point, but their cry of help was often unheard until the point of crisis or beyond:

I think it's too long to wait for that length of time and I think and it's very difficult. I was actually at times frightened of how ... where is my breaking point with them and I don't want to go there because I'm quite easy, I'm quite laid back and I don't ever want to do ... I was actually scared of harming the children and I don't think I should ever be at a stage ... if someone phones social work ... when they've looked after their children all to the best of their ability and under such tough circumstances, they should phone you that same day; someone should phone you up. It shouldn't come to crisis either, I think it should be offered at diagnosis (Female parent 5, interview).

Parents spoke about the time taken for a social worker to make contact and the processes that had to be followed prior to any actual help being offered (e.g., respite). This time delay could arguably push the parents to breaking point by the time help was on offer:

I mean, we have had this for four years, nobody phoned us, nobody asked us, nobody knows us, we were absolutely horrified and now we do get somebody that gets in touch (Female parent 2, interview).

Parents were mostly of the view that unless there was an emergency or breakdown, they should not be expecting help from social work. There was a sense of frustration among parents whose cries for help seemed to go unheard for a long time. Parents felt that the social work apparatus was geared towards responding to crisis rather than being proactive. Parents were made to feel let down and over-stretched before any help was offered:

Did other people get it because ... we will check into the local mental hospital because we can't cope and maybe you will help us then. Do we have to feel rather than cope (Female parent 1, interview)?

Two of the three study local authorities had internal guidelines in place stipulating the time frames for making initial contact and completion of assessment, as discussed earlier in this chapter. Although the data did not indicate whether the time frames were adhered to, they do suggest that having to wait for help, often for uncertain periods of time, was frustrating for the parents:

And a lot of these families break up, you know real disasters ... Normal family, yes you can cope with a few of these things but if you have got a child with autism, so much of your energies are focused on just coping with it, it leaves very limited scope to deal with other slings and arrows of outrageous fortunes that happen to people anyway (Male parent 1, interview).

Parents were also of the view that help should be offered proactively rather than them having to chase social workers:

When your child is first born you only get the midwife coming out and the child support team coming out for a couple of weeks just to check up, and make sure everything is okay. I think you need something like that for autism diagnosis as well, people who just check how you are doing and see what services you need as parents and where they need to go for counselling or what kind of support you and your child might need (Male parent 4, interview).

However, one female parent who did not have a current social work intervention said that she took the initiative to seek help when her son was

diagnosed. She participated in a parenting course that helped her to deal with her son's autism in a confident manner:

I got in touch with the Carers' Centre ... that was when it opened up, they got me into a parenting course and I would say that parenting course was the determining point for me. It was a complete turnaround and I haven't really looked back since then (Female parent 12, interview).

Other parents who did not have social work interventions argued that they either did not receive an appropriate response from social work or did not know what help was on offer:

No, I don't get any help from social work services. Before we had tried it, I had a social worker who come out and did an assessment and then she got moved and that was the last social worker I had. I phoned social work services several times, they didn't get back to me (Female parent 13, interview).

I: Have you heard about social work assessments?

No, I've never had that (Female parent 11, interview).

Social workers and operational managers shared the view that help from social work was on offer all the time but that parents sought help from social work at the point of breakdown. They summarised that the following interventions or help were on offer for children with disabilities, which included children with autism and their families.

The age of the child(ren) with autism who was referred to local authority social work did indicate that they were primarily engaged in education. The study found that children with autism thrived better on structure and routine (see previous findings chapters). Attending school on a day-to-day basis did provide a routine. School holidays were identified as the most difficult periods for a parent of a child with autism. School holidays meant a break in routine that might trigger behavioural challenges. Short breaks (clubs, play schemes) or long breaks (overnight respite) were two of the main services offered by social work:

Most if not all my families have children who do not have autism as well so they have got siblings they want to think about, and for most of the families, they feel a lot of guilt that they don't get to spend the same amount of time with the other children. Few parents maybe they just want a bit of break or time for themselves ... I would think, they can't, children with autism, most of them need so much of structure and routine so they can't be flexible or spontaneous. Like many of our parents, very difficult time for parents is the summer holidays. If they are not in play schemes, the autistic children they are at home with possibly other siblings who want to go and do things and it is just not possible (Social worker 1, interview).

That overnight respite because we've had such difficult summers, actually stretched to capacity at every minute because we've tried placing other children in crisis centres in other environments and they've not coped (Social worker 4, interview).

Children with autism and their families also approached social work for emotional support and practical assistance such as advice on welfare entitlements, referrals to organisations that dealt with the dietary or sleep difficulties of the child with autism and so on:

Sometimes it's just about an acknowledgement from a professional that actually it's very difficult and that's the first expectation that people will try and understand (Social worker 5, interview).

We often give them a list of services that are available without social work involvement, things that they can just access themselves, charity things, clubs in the community, that sort of thing ... often we can give advice to the family about who can come into help such as ... other thing is we can get and make referrals to other while working on the larger assessment (Social worker 1, interview).

According to the social workers in this study, help with behavioural issues and challenges presented by a child with autism were other reasons for contacting social work. Social work could perhaps play a coordinating role to streamline support for behavioural issues from their health colleagues working in the children and adolescent mental health service or other services:

CAMHS [Child and Adolescent Mental Health Services] ... now have this intensive team that we have been working alongside and they are taking a much bigger role in the management of behaviours within homes and things and supporting parents and that is really my first in the whole time (Social worker 3, interview).

It was interesting to note both parents and social workers acknowledging the need for intervention or help to be facilitated as early as possible. From the social worker perspective, it was the parents who were arguably not forthcoming in asking for help until they were desperate. In other words, social workers argued that the parents did not request existing help on offer at the time of need. This would then be classified as delayed help rather than real-time help:

Families tend to, by the time they come to us are already on their knees. They are not keen to accept support really before that or they don't know what is available or they are not sure what they want until they really need it and then they don't care what it is (Social worker 3, interview).

Quite often they're coming to you and they are in a very desperate state, so actually there's a relief to engaging (Social worker 5, interview).

The social workers were expecting parents to be patient with the social work process of delivering help. They appeared to be preoccupied with the intricacies and process of delivering help; their appreciation of the parents' difficulties of living with a child with autism seemed to take a back seat. The pressure to balance demands for help against available resources may have attuned them to prioritise the needs of one child against the other. The Section 23 social work assessments mentioned in the previous section also appeared to focus on identifying the risks and challenges. This complemented the parents' perception that their pleas for help were unheard until breaking point. It also indicated that the existing social work apparatus took a reactive crisis-driven approach focusing on difficulties rather than a proactive early-intervening approach focusing on strengths:

I mean families can be very demanding and quite rightly so they want what's best for their children ... but sometimes

they forget there might be a few 100 other children who have the same needs, or other needs and they have to be apportioned and they have to be sort of delivered out equally, if you like, or as best as possible and families become very frustrated with that, because they feel that they should have access to services very quickly (Social worker 6, interview).

The only criticism I have for this one, that it doesn't support the assessment to be written in a style that actually builds on existing skills and abilities that the young person and family have. Because if you base your assessment on the positives, skills and abilities you don't get a high score obviously because you need to evidence the difficulties (Social worker 2, interview).

9.3.2 Peer Contact

The previous chapter identified that networking with other parents with similar experiences was a positive source of support for parents. Parents and social workers viewed peer contact as a helpful resource in dealing with autism. Peer contact appeared to offer an informal platform of learning and sharing, especially during the early stages when parents were struggling to make sense of autism. They felt listened to, not just heard; in other words, they were able to better connect within their peer group because autism was the common denominator in their lives. Parents also spoke about the embarrassment of taking their child with autism to visit their friends or family, because of the unpredictable nature of the environment and their child. These inhibitions were arguably much less when they became aware that the experiences of other parents were similar.

As established in the previous chapter, the informal network of support from families and friends was rather limited for parents of a child with autism. However, the data also indicated the need for facilitating peer contact for parents of children with autism to build the circle of support and companionship for both parents and their child. Although the benefits and strengths were recognised by the parents and the social workers in the study, the data did not suggest any initiatives to build and develop this as an effective support mechanism for the parents. Encouraging shared care

among families involving taking turns to share the care of their children and have a break, could be a step in this direction. This could also be a potential solution to the social isolation that parents spoke about earlier in the study:

The help from maybe other parents who have got autistic kids, I think would be a great help ... rather than speaking to experts, you know, people like that. To actually be able to speak to the other family in this day and age who have experienced a little bit for instance ... now I can probably help somebody, you know. I can tell them what to expect roughly how he got to deal with it, yeah I think so. I think that would be a good idea (Male parent 9, interview).

I think the most effective support is peer support ... They enjoy spending time together and sometimes it is the most beneficial support because they don't need to justify and they don't need to evidence that they still need the friendship to be there (Social worker 2, interview).

9.3.3 Autism-inclusive Help

The study found that when autism coexisted with a learning disability, it opened the gate to help and resources that predominantly existed for learning disabilities. An example of this was community learning disability nurses. It appeared that there was a greater inclination towards fitting the disability around the existing boxes of services/help rather than considering how help could be moulded around the specifics of the disability. The data suggested that the knowledge and understanding of autism and its variants were vague, with professionals often confused between autism and high-functioning autism (Aspergers syndrome):

I think the barrier might have been that they needed to have a learning disability to be able to get into various services. So there weren't services that were developed purely for, you know, an intelligent and young person who had autism and I think that's been the difficulty for some of them (Operational manager 1, interview).

think that goes back to the knowledge base and the training for these specific groups and for the wider community about understanding autism, understanding difference (Operational manager 3, interview).

Maintaining structure and routine was key to the management of autism as identified in previous chapters. The venues of help were dotted around in the community and to meet their needs, the child with autism may have had to dip in and out of different services. This did not provide the structure and routine that works best for children with autism. This suggests the need for a review and reflection of service delivery from an autism perspective:

I think in the case of autism it should be important that the structure is tight and that's often, I think, why sometimes our children end up in autistic-specific residential service because sometimes ... some parents ... perhaps the family of the child can't cope with what's involved with moving around different services, a bit here, a bit there; some autistic specific, some not, but there comes a point where actually you really do need staff that are specifically trained and are going to understand autism to hold it together for the family so they feel held and more secure and the child feels more secure, because usually the biggest issue is the level of anxiety in the family, in the child and the relatives(Social worker 5, interview).

The data also flagged that the lack of confidence of social workers may have been triggered by the insecurity associated with not being autism aware, or not having good knowledge of autism. Hence, social workers sought out specialist expertise for the child with autism and their parents. This reinforced the need for autism-specific training for workers in the local authority social work:

I think we need a specialist from another organisation to explain behaviour management or those sorts of things that take away a little bit of that professional responsibility that you've got because it's such a specific area of knowledge (Social worker 4, interview).

I think probably that's because it's very specific. Most people, myself included, aren't particularly autism aware, so the needs of a child with autism are quite unique perhaps (Social worker 10, interview).

However, professionals did not experience that the use of help offered by autism-specific voluntary sector organisations produced a significantly different outcome for the child with autism and their parents:

I think maybe not specific. No, I'd say probably more about challenging behaviour. I don't know, it would depend. It depends on what the child does because I work with someone else who is in an autism-specific service, a very, very spark of genius, I don't think they've moved her on ... And then they're meant to be a specialist. So, I mean they, her life is just sitting in her bedroom listening to music and going out on three-hour car journeys and they're meant to be a specialist (Social worker 9, interview).

9.3.4 Summary

The help that was currently available for autism appeared to be fragmented and disjointed. The onus still predominantly rested on the parents to reach out for help, which the parents expressed was something they could be better supported with. They were of the view that they should be able to access help more or less seamlessly and that help should come to them. However, the study found that autism was not yet grabbing the attention of the social work professionals as it might child protection, despite the fact that all three study local authorities had dedicated teams for children and families with disability. Parents were keen to have the choice of someone taking on the role of coordinating and streamlining the help for them, rather than them being expected to multitask when they were already struggling given the challenges of autism. Lack of a continuing and proactive mechanism of help did make the parents feel let down and not appropriately supported:

sometimes feel actually social work they are there for when you abuse your child but they've got a disability team. They obviously aren't there for just when you abuse your child and I think it should be explained properly to you what they can do for you, which I really wasn't aware of at all at the time. I was handed a leaflet and I was handed a booklet about what's available, what charities, etcetera but that's not enough (Female parent 5, interview).

Therefore, it could be summarised that although social workers acknowledged the need for assistance for this client group; there was a wide gap between what parents identified as beneficial for them and what and when it was offered. This contributed to parents having a restrictive QOL experience.

The next section examines some of the difficulties and challenges experienced by the parents when engaging with social work.

9.4 Disempowering

The study found that parents did not feel supported or helped during their engagement with social work. Difficulties accessing information about the services available from social work contributed to this experience. Parents indicated that social workers' limited awareness of the hidden nature of autism also made it more difficult for them to argue their child's case. The mismatch between the expectation of help and what was available was another aspect making the experience far from satisfactory.

9.4.1 Insufficient Information

Some of the specific difficulties associated with autism (unpredictability in behaviour, lack of spontaneity), unique to this condition (discussed more elaborately in previous chapters 7 and 8) implied that parents would appreciate any help offered. The study found that parents identified social work as one of the main hubs for information and help. However, the experience of parents with social work was anything but proactive in the sharing and dissemination of information. Having access to the appropriate information (respite, behavioural input) could assist parents to utilise it to their advantage. Parents were disappointed that the very mechanism of help that was established to enable and promote the wellbeing of the child with autism and their parents was failing them by not performing even its most basic function: offering adequate information with regard to the help available.

Very few professionals in social work tell you that actually you could get this and that. Why are they not doing it? Because ultimately if you could take the stress off a family, the child will benefit. So, why not make it part of the job to say all the benefits as a common norm to do (Male parent 2, interview)?

I think that they should tell you what's available out there, that you shouldn't have to find out yourself and they don't sit you down and say, 'right well this is what's available and you would be entitled to this'. It's what I feel personally and I know other parents that feel it (Female parent 7, interview).

9.4.2 Inadequate Knowledge

As discussed in chapter 7, autism is a disability in disguise primarily because a child with autism does not provide any clues in their physical appearance to suggest that they have a disability. Parents in the study said that social workers misconstrued the demands and challenges associated with autism because of its hidden nature. This raised the bar for negotiations and conversations they had with social workers. It placed an expectation on parents to be quite articulate about their needs as well as the needs of the child. It appeared that parents who did not have the confidence and communication skills to advocate for their child's needs were less effective at arguing their case with the social workers. This experience was disempowering, especially for the female parents in the study who communicated with social work and were the point of contact with social work more frequently than were their male counterparts. This shed light on the need for ongoing training and professional development of social workers to provide them with a deeper understanding of autism and encourage them to be more sensitive and alert to the child with autism and their parents. This study calls for social workers to be more receptive and attuned to the world of autism to deliver help more effectively:

Especially I think with autism, I don't know if it's different with a child with ... that's maybe in a wheelchair, you know cerebral palsy or Down syndrome where right from they're a baby, they know that they've got disability. With autism, it's like actual thing and it's you having to phone up and say I'm not coping here, my child's wrecking here, my child is wrecking the house and he's not sleeping and he's just causing havoc. That's the one thing that's hard about autism, it's like a hidden thing and it's not until you're living in a house with the child that you've then got to explain to people a child's doing this (Female parent 7, interview).

It's all on their terms. They prefer their terms at all times. So it's very tough to negotiate with them (Female parent 5, interview).

9.4.3 Non-streamlined Help

Parents and social workers argued the case for help to be streamlined for children with autism and their families. Parents called for service planners and decision makers to be mindful and sensitive to the needs of children with autism when planning services. However, that does not necessarily imply that it was a call for specialist help; rather it was a cry to be autism inclusive when planning disability services. Parents also spoke about the need for more local, age-specific programmes with increased provision during school holidays. Families of children with other disabilities share these views (Lancaster, 2012). This suggests that parents were seeking out more streamlined help rather than specialist help:

and during school holidays that there was a programme I could put them in. I'd rather have something local where they could go to, maybe even a morning ... It's great to have these children in sports, but for a group from 8 to 18, it's a huge age gap that I think he should be in a group from 8 to 12 because I don't think ... we dropped him off and there was ... there were no one from his age and we feel that is wrong ... we need to have something specific for people with learning disabilities, autism. You can't just put them together with people in a wheelchair. They really need to consider the needs for them ... I wish it was in a local pool rather than me having to drive three-quarters of an hour to for half an hour, which I felt was a bit ridiculous really and it was lovely and it was really nice but I wish it wasn't... (Female parent 5, interview).

It was interesting to note that the parents' requests for streamlined help were often interpreted by the social workers as a need for specialist help. Social workers viewed current service providers as not competent to work with children with autism. This again highlighted the need for training across the spectrum of staff involved in delivery of care for children with autism and their families:

We have a rhythm, which allows us to hold us together in a routine and I think they need that. I think their rhythm needs to include opportunities to spend time in autistic-specific settings (Social worker 5, interview).

there is huge unmet need for children with autism. They need more support, they need it for longer. They probably need more autism-specific supports. They need more people who know how to work with children with autism. Some of our outreach services don't have sufficient training (Social worker 3, interview).

9.4.4 Summary

Parents in this study who accessed social work services experienced frustration, disappointment and a lack of confidence with the social work apparatus, making them feel disempowered, which led to their QOL experience being restrictive.

The following section sheds light on the analysis that led to the conclusion that social work was not engaging well with the parents in the study.

9.5 Non-engaging

The study found that there was a general sense of increasing demand for services from social work from this parent group. Social workers reflected on the type of cases they had, to indicate this increasing trend. Not surprisingly, the operational managers across the three local authorities had also observed a pattern in the increased demand for help from this client group:

Yes, absolutely I've seen it and I'm not clear if that's because more young people are getting diagnosed, diagnosis early, people are aware of services. I'm not clear, but definitely a growing number of referrals for children who have an autism diagnosis. Absolutely (Operational manager 2, interview).

but I would say that more and more children are being diagnosed with autism, and so they would be ... I mean that group which started off with being a bunch of mums with their autistic children on a Sunday afternoon driving over a hundred people come to it ... so that one itself demonstrates that demand is increasing (Social worker 9, interview).

There was a sense of ambiguity among professionals as to why there was an increase in diagnosis. One perspective was that child(ren) may have always had the symptoms, which was perhaps consistent with the improved diagnostic process and increasing public awareness of autism in recent years. Another impression of the reason for this was an actual and definitive increase in the number of children and young people having autism:

there's probably an increase in the precedence of the fact that more children are now being diagnosed or have been for a number of years, whereas before the child who had been diagnosed with kind of symptoms, but nobody quite knew what it was. So yes I think there's been a lot more awareness in years (Operational manager 1, interview).

like in the whole of Scotland and UK and whole of north Europe there is more children diagnosed with autism than ever before (Social worker 2, interview).

Another explanation was around the type of jobs that the parents of children with autism had and its apparent genetic association:

some people said well in ... there's a lot of industry which is IT oriented and there might well be families where there's a genetic link. People think that perhaps there's a particular vulnerability. There's the other possibility that we've got, very active paediatrician who is very good in identifying autism and so perhaps then that degree of diagnosis might be higher and it's really hard to determine why that might be (Social worker 5, interview).

Although the study acknowledged an increased demand for help, the parents did not experience engaging social work. Coded as 'barriers', the next section examines barriers identified in the study that social workers felt hindered effective engagement with the child(ren) with autism and their families.

9.5.1 Barriers

The study found that social work professionals expressed a lack of confidence in their ability to deal with autism. They were of the view that they did not have the expertise to deal with this. According to this study, in

addition to raising the awareness of autism (as identified in the previous chapter), training opportunities for social workers to develop their knowledge and skills in the area of autism should be seriously considered

I think there's also an attitudinal challenge about these children from both public or perhaps professionals that don't have or are not as familiar with this client group (Operational manager 1, interview).

I think as well there is that feeling of being a bit disempowered as well, that families feel they're coming to you asking for help I don't know what to do and actually well I'm not sure I can tell you exactly what to do (Social worker 4, interview).

Another emerging finding was the difficulty involved in communicating with a child with autism. As highlighted in the previous chapter, parents found that communicating with their child was a huge challenge. The social workers in this study shared this concern. Communicating with the child and obtaining their views was embedded in the ethos and values of social work practice (Scottish Social Services Council (SSSC), 2015). It was disappointing to note in the study that social workers were not demonstrating good practice by pre-empting the communication needs of the child with autism and utilising alternative communication methods (e.g., PECS, Boardmaker) to connect with the child. This further questions the quality of the needs assessments undertaken by social workers and their real understanding of what is needed by the child and the family:

some of them don't have the same speech and language that other children would have and so they're unable to express their views. They're unable to tell you what their needs are or how they feel about disability. It's very much more about engaging with parents and carers or other service providers who are working with that child (Social worker 6, interview).

the most basic thing is not having a grounding in PECS or Boardmaker ... like I've got some grounding in alternative communication but I don't carry a book of pictures with me (Social worker 4, interview).

Yet another finding that highlighted unsatisfactory engagement with social work was the analysis around carers' assessments, as discussed next.

9.5.2 Carers' Assessments

The study found that the uptake of a carer's assessment ('Section 24 assessment') by parents was very low across the three study local authorities. Social workers were of the view they were getting better at offering Section 24 assessment to the parents as part of completing the Section 23 assessment for the child. However, they did not appear to appreciate the purpose of the carer's assessment. The study also indicated that a stand-alone carer's assessment did not give carers access to the services they were entitled to. However, it could perhaps trigger a referral to appropriate services in the third sector or other services of the local authority. When done in conjunction with the Section 23 assessment, it perhaps added strength to recommendations for accessing a gated service for the child with disability:

I honestly don't know because I've done carer's assessments ... I don't actually know what the purpose is of them (Social worker 10, interview).

Obviously our focus is to assist the child's needs and get the services in place for the children but, for example, if something comes up as part of Section 24 carer's assessment, it is more linking the parents with the right professionals and signposting them in the right direction like counselling or peer support or advice from appropriate professionals (Social worker 2, interview).

I have not had one carer yet, who wanted a carer's assessment. I mean, in all my assessments, it asks, 'have you offered the assessment?'; I have said yes, but parents have declined. I have not had any family yet that wanted to do that (Social worker 1, interview).

In contrast to the experience of Social worker 1 as expressed above, the great majority of parents in the study claimed that a carer's assessment was never offered to them. They did not appreciate that they were entitled to an assessment of their own needs and said that it was not offered to them:

I: Have you been offered a carer's assessment, since you are the main carer?

Female parent 4: No.

I: Have you ever been offered what's called a carer's assessment?

Male parent 7: I don't know. My wife would be the best one to answer that.

9.5.3 Direct Payments

Direct payments gave the local authority the opportunity to offer an alternative to the provision of care, by making direct payments to the child with autism and their parents, enabling them to arrange their own help for assessed needs.

The study found direct payments perhaps offered flexibility and choice for children with autism and their parents to arrange help that they thought was beneficial for their needs:

but also you know have access to direct payments and you know we very much, I believe we try very much to enable, you know families, parent-carers, as well as young people to have as much choice and direction in relation to package support they have been provided with and that is along the ethos, of course, of directed support (Operational manager 3, interview).

The data suggested that direct payments were offered as an option to parents of children with autism; however, it could be argued that the uptake of direct payments was not high across the three study local authorities:

We offer direct payments as standard; unfortunately we don't have many packages in place (Social worker 2, interview).

And I haven't put into place any direct payments for anyone (Social worker 6, interview).

The study found that processes involved in setting up and managing direct payments were far from straightforward; this may be because social work professionals did not feel confident and competent to roll out direct payments. Limited uptake would imply that social workers may not have had

the opportunity to have a first-hand experience with direct payments. This could perhaps act as a deterrent when discussing potential direct payments with parents and children with autism. It also emerged from the study that parents would have to focus a lot of time and energy on setting up and managing these payments because they were effectively becoming employers. This appeared to be another huge demand placed on them in addition to the demands of managing their child with autism. However, the study unearthed one or two examples in which direct payments had a great influence on the lives of child with autism and their families:

It is definitely only really our more professional parents or more middle class parents that are taking that up I think ... I think once it is up and running, it is a great thing. But the whole process of getting your heads around it and learning everything like that takes quite a while, quite a lot of energy and input by them to do that ... I struggle with the intricacies of their insurance and their training and everything like that and how they are going to pay for that, to manage that and then payroll and things. And I think when they have so many other things they have to deal with; it is very difficult for them to take that on board (Social worker 3, interview).

I work with a particular family who have two autistic children who also their kids were finding it really difficult to build relationships, so whoever we would send, one of the girls just vetoed. So it's really difficult for them to get the support staff. Now they've got their direct payments and it's just like night and day. It's really changed their lives (Social worker 4, interview).

It can be concluded from the study that direct payments did come with its benefits of choice and flexibility, but that parents and professionals would require a lot of help, advice, guidance and less-cumbersome procedures to encourage its uptake.

9.5.4 Summary

How parents experienced their engagement with social work was another aspect of their QOL experience. The discussion around the barriers that hindered positive engagement with social work, and the not-so-popular

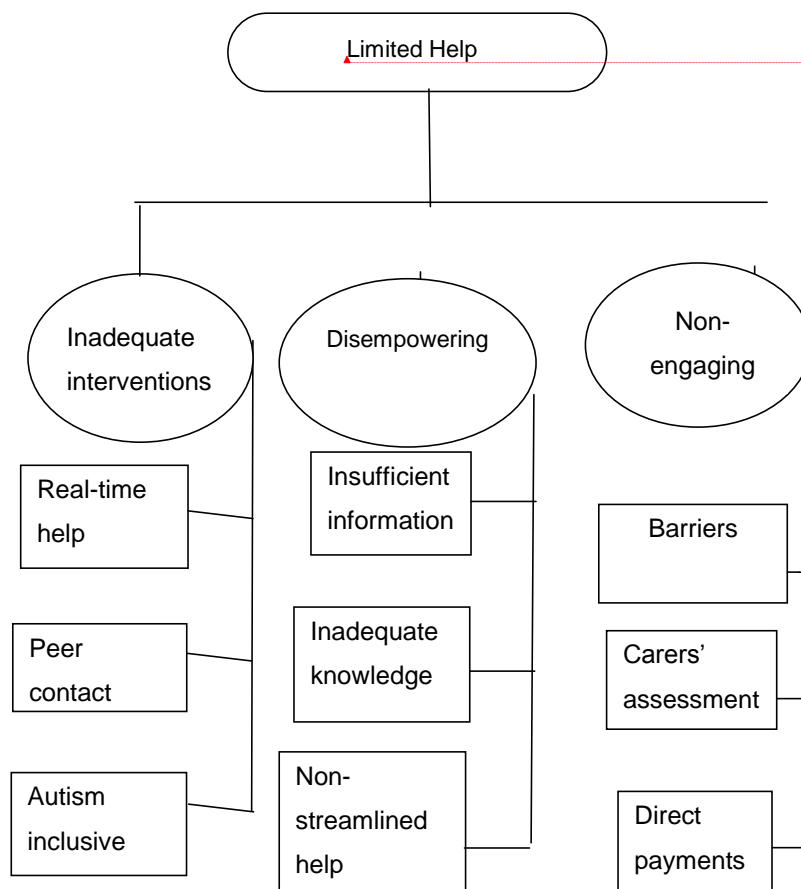
approaches around carer's assessments and direct payments suggested a non-engaging social work apparatus, making the experience further restrictive.

9.6 Conclusion

The first part of this chapter presented a descriptive account of the structure, processes and procedures of social work across the three study local authorities. Comparison across the three study local authorities further enriched the descriptive account.

The second part of the chapter reflected on the parents' perspectives on the help they received from social work and its influence on their QOL experience.

Figure 10 is a pictorial representation of the main category, subcategories (property) and codes (dimensions) that emerged using the axial coding process in the grounded theory analysis.



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Figure 10: Properties and dimensions of limited help

Parents summarised that the help they received from social work to assist in the day-to-day management of their child with autism was rather limited; hence the overarching category 'limited help'.

The analysis began by exploring parents' opinions about the help on offer from social work. They expressed that the interventions were inadequate, hence the coding 'inadequate interventions', which meant they were (a) unable to access help in a timely manner (coded as 'real-time help'), (b) focused less on facilitating engagement with other parents in similar

circumstances (coded as 'peer contact'), and (c) suggested the service provision should expand and develop to be autism inclusive (coded as 'autism-inclusive help').

The second property (subcategory) 'disempowering' summarised that parents did not feel optimistic and positive about the social work apparatus because of the difficulty in accessing appropriate information about the help available (coded as 'insufficient information'); the lack of knowledge and skills acknowledged by professionals in the area of autism (coded as 'inadequate knowledge'); and the non-availability of the actual help parents were looking for (coded as 'non-streamlined help').

'Non-engaging' was the third (subcategory) explained under the dimensions of barriers, carer's assessments and direct payments.

These three properties represented the parents' perspective of the limited help they received from social work and this contribution to their restrictive QOL experience.

The discussion chapter (chapter 11) brings together the dynamic nature the category limited help in creating a oppressive quality of life experience for parents.

Chapter 10: Literature Review update

10.1 Introduction

As indicated in the beginning of literature review chapter (chapter 4), an initial literature review was completed prior to the data collection to know 'just enough' in order to maintain an open approach to the data emerging from the field. Post data collection, systematic literature review update was undertaken to familiarise with the most up-to-date thinking in autism research. Doing literature review in a staged manner particularly when in tandem with the emergence of the grounded theory has assisted in scrutinising the relevant literature with the view of placing the 'theory in literature'. This chapter is dedicated to outlining the current and up to date literature with an eye for identifying the potential gaps in knowledge which the emerging theory could fill. The discussion chapter at the latter end of this thesis encapsulate 'locating the theory in literature' by marrying the gaps with the findings of this study.

Criteria for inclusion in this literature review consisted of studies (a) published between 2010 and 2017; (b) published in a peer-reviewed journal in English. The search was predominantly focused on peer-reviewed journal articles and did not include publications that did not undergo peer review. Keywords used in an electronic search of databases included autism, autism spectrum disorder, parents, mother, father, parenting, quality of life, social care and social work service. Additional articles were identified in the reference sections of articles retrieved from the databases and of review articles and book chapters on these topics.

I had noticed that a large proportion of the literature is situated in medicine and pharmacology. In comparison to this, the literature available in social science space was noticeably less. Amongst the small proportion of literature present, researchers in the field of psychology and education were identified as biggest contributors. I also observed that the database of autism is ever growing, for example when I began searching for new literature in the

beginning of this year (2017), a general electronic database (subscribed to by the library of university of Edinburgh) search of the keyword autism (across all disciplines without using any exclusion criteria) gave approximately twenty thousand hits. A repeat search in the middle of the year approximately six thousand more search results than the previous one.

It is important to spell out at this juncture that all literature updates included in this chapter should be read in conjunction with the earlier literature review consolidated in chapter 2 and 3 and 4.

10.2 Autism - 'contested category'

Autism has been a growing topic of public and professional interest over the past three decades; literature search evidence that there has been a substantial increase in research interest on autism particularly over the last two decades. Despite the increasing documentation of research activity and publications in this area, it is an irony that it is still quite difficult to talk about this entity which is sometimes called "autism". There is a range of vocabulary found in the literature which includes (not exhaustive) "autism spectrum disorder", "autism spectrum conditions", "the autism spectrum" or simply "the spectrum". Depending on the terminology used, it reflects different stances: rejecting or accepting to view it through the lens of the medical model (deficit focused language), stressing the concept of spectrum and so on. Hence, it can be implied that there is greater or lesser unity between the terms. The most recent edition (fifth) of the Diagnostic and Statistical Manual (American Psychiatric Association, 2013) refer to this condition as 'autism spectrum disorder'. While I have used a number of aforementioned terms interchangeably across the length and breadth of this thesis, my preferred terminology is 'autism' for the simple reason that it helps me to remain open to the many ways in which it is used and adapted.

The literature sheds further light on the active controversy regarding not only its nomenclature but aetiology, diagnosis and treatment strategies. Moreover, there is also a strong presence of self advocates with autism who

is rejecting the language of 'disorder' and has embarked on the movement of neuro diversity (refer to this in more detail in chapter 1). As a budding social science researcher attempting to make sense of this ever evolving, ever changing phenomenon; Silverman (2012, p16) finally summarised it for me by choosing to refer to autism as a "contested category". And contested categories has always attracted interests from researchers, professionals and public alike. This further underscores why this research study is contemporary and relevant.

Contemporary thinkers of autism like Ruud Hendriks, author of 'Autistic company (2012)', Chloe Silverman, author of 'Understanding autism (2012)' and Joyce Davidson and Michael Orsini, authors of 'World of autism (2013)' has encouraged researchers to take a critical and constructivist approach to studying autism giving particular attention to a number of anthropological aspects. One aspect of specific relevance to this research study is the need for attention to the lived experiences of people with autism and those close to them, which in the context of this research study are parents of the child with autism. Of the three authors, I was more inspired by Silverman's (2012) focus on love as a theoretical lens to formulate her arguments to base her study on parents. She argues that autism has been perceived as a 'disorder of love' whether that of a parent as in "refrigerator theories" or a person with autism as in the theory of mind. Secondly, parents have been historically involved in research and treatment programmes bringing parental love into scientific research. While the focus of Silverman was to understand the complementary relationships between science and parenting, the scope of this research study is to personalise the experience of parenting and situate it in the larger canvass of quality of life, thereby responding to the authors' call for studies centred around parents.

The sections that follows present those literature updates that look at developments if any in prevalence rates and the most up-to-date thinking on diagnosis and treatment.

10.2.1 Prevalence

Skyrocketing prevalence rates for autism continues to be reported throughout the world. Baio (2014) makes reference to the findings of the Centre for Disease Control and Prevention (CDC) of the United States of America where 1 in 68 children are claimed to be affected by "autism spectrum disorder" (DSM-V). McDonald and Paul (2010) embarked on a large scale study of the data sets from Denmark, California and Japan to understand if there is an increase in cumulative incidence of autism, the findings of which endorse a continuous increase. In the United Kingdom (UK), it is estimated that 1 in 100 people have autism. The latest prevalence studies in the UK is based on the data collected from the 2011 UK census. It is estimated from this data that 1.1% of the population in the UK is on the autism spectrum which equates to approximately fifty thousand people in Scotland (geographical location of this research study). There is a clear absence of more up to date prevalence studies particularly in Scotland. The report published by the Public Health Institute of Scotland in 2001 (reporting 0.6% children have autism) and the Audit of services for people with autism in Scotland completed in 2004 continues to be the two main sources documenting the prevalence rates in Scotland. More and more researchers have been interested in the gender divide in autism with the latest study by Fombonne et al., (2011) claiming that five times as many males as females are diagnosed with autism. Gould and Ashton Smith (2011) argue that autism is under diagnosed in females. Although this research study is not quantitative by nature, basic quantitative data that was collected to describe the demographics of the sample would be a value addition in literature particularly when there is a dearth in quantitative and qualitative studies on autism in the Scottish context.

While the debate about the nature of increasing autism continues, the potential for this increase to be real and involve a combination of genetic factors and exogenous environmental stressors exist. Reilly et al. (2017) conducted a systematic review of the studies on the genetic factors of

autism; they argue that there is significant progress in genetic exploration with the diversification of research into mapping autism candidate genes, assessing the nature and frequency of gene mutations, insights in to related molecular path ways and autism related brain regions. Change in diagnostic criteria, early age diagnosis and inclusion of milder cases of autism are argued to be some of the candidate exogenous factors implicating an increase in autism incidence (McDonald and Paul, 2010). Although understanding or exploring the aetiology of autism is beyond the scope of this research study, the data gathered could provide insight in to what the parents think about their child's autism.

10.2.2 Diagnosis

One of the most radical and note worthy advancements post the completion of data collection was the commencement of substantial revisions in both the major psychiatric classifications viz the American Psychiatric Association's (2000) Diagnostic and Statistical Manual or DSM- IV and the World Health Organisation's (1992) International Classification of Disorders or ICD-10. The launch of DSM-V in 2013 provided a renewed diagnostic label for autism whereby the diagnostic subtypes or labels like Aspergers and Retts was removed and the condition in its entire heterogeneity is called "autism spectrum disorder". It is expected that a similar revision of the ICD is in progress with the publication of ICD-11 expected to be in 2018. While this research study did not include children or parents of children with Aspergers, the revision is still critical as its potential implications on eligibility of services, public perceptions and diagnostic assessments remains uncertain. A detailed summary on the introduction of DSM-V and its consequences on this research study has already been documented in chapter 1.

Families are often highly invested in the search for an explanation of their child's behaviour, and parents of children with mental health concerns may seek a non-blameworthy explanation for the child's behaviour, such as diagnosable conditions or genetic explanations (O'Reilly and Lester, 2015).

Diagnosing autism is complex and time-consuming; culmination in an autism diagnosis is complicated by multiple factors: variation in clinical practice, the heterogeneity of presentations and co-existing conditions (Karim et al., 2012). For families, there is typically a latency of around three and a half years between first contact with a professional and final diagnosis, with an average of one year between families' first concerns and the point at which they initially raise these concerns with a professional (Crane et al., 2015). In a landmark UK study of 1200 parents, children with autism were diagnosed on average at 6 years old, despite parental identification of symptoms at 18–24 months (Howlin & Moore, 1997). Parents often report high levels of stress (Crane et al., 2015) and negative experiences (Osborne and Reed, 2008) during the overall diagnostic process. However, in contrast to this are the findings in a study based in Northern Ireland (n=11 mothers of children aged between 5 and 11 who received an autism diagnosis eighteen months prior to the study) that specifically looked at the parents' experiences of diagnostic process for autism spectrum disorders conducted by Jane Braiden et al. (2010). Results suggested that the majority of parents had positive comments about the assessment and diagnostic experience. Parents cited several points as contributing to their overall experience with the process. These included having their initial concerns listened to, receiving their child's diagnosis in person, receiving written information and help in applying this information.

The only study which examined parental stress specifically relating to the diagnostic process (Siklos and Kerns, 2007) found that parents of autism children with more severe communication deficits reported lower stress in relation to the process of diagnosis. The authors proposed that greater severity of autism symptoms were clear indications of significant problems and the process of diagnosis was more of a starting point to accessing services rather than a complete surprise.

Reilly et al. (2017) argues that parents more often than not first raised the possibility of the presence of an autism diagnosis through "building a case",

which professionals were then able to ratify or negate. There is a direct implication that it is parents who argued for the autism diagnosis and whilst this may be followed by a grieving process, an explanation of their child's presentation seem to be the parents' priority. It is noted that this study was conducted in a Child and Adolescent Mental Health (CAHMS) setting in the United Kingdom with 28 parents who were opportunistically sampled. Parents are often more satisfied with the diagnostic process when they were given opportunities to ask questions, when professionals took into account parents' early concerns, when useful information was provided by the professionals and when the professionals engaged with the families in a supportive and empathic manner (Brogan & Knussen, 2003). Banch et al. (2010) further argued statistically significant improvements in the advocacy skills and self efficacy of parents coping with a child's diagnosis when they are proactively supported in a post diagnosis support group.

Given this is an age of austerity with reduced funding for all services, universal, specialist and social care alike, it is interesting to review a UK study conducted by Karim et al. (2012) that explored how diagnosis is managed in the real world by professionals (n=26 that includes child and adolescent psychiatrists, community paediatrician and educational psychologists). The results indicated that despite the existence of National Institute of Clinical Excellence (2011) guidelines to ensure consistency in diagnostic approach, there is considerable variation. The pressure of time is also identified as a consistent difficulty. Although NICE advocates for multi disciplinary approach to autism diagnosis, this is often hindered by problems (communication, eligibility criteria) in coordinating different professionals or the practical issues when there is an increasing number of children referred for diagnosis. The study also found that there are no consensus among the participants in the terminology used to describe the condition - a myriad of terms are used with some participants avoiding the use of certain terms to protect families from stigma, but in potentially unhelpful for services and families.

Reilly's claims of parents building a case for diagnosis and Siklos and Kerns argument of parents of children with severe autism having lower stress levels are interesting stances which has a scope for a compare and contrast analysis with the findings of this research study. While diagnosing professionals are not the participants of this study, the literature identifies that factors that contribute to an overall positive diagnostic and post diagnostic experience. It is worth analysing the data to elucidate the Scottish parents' experience of the diagnostic process with an eye on any specific suggestions or recommendations from the parents that is applicable specifically in the Scottish context.

10.2.3 Interventions

From the point of receiving their child's diagnosis, and throughout their child's life, parents make decisions about which interventions to use with their child. This has been described by some parents as an overwhelming and difficult process (Valentine, 2010). Interventions can also be offered pre diagnosis which may then continue post diagnosis, which is sometimes referred to as "early intervention". Vinck Baroody (2016) completed a quantitative study that investigated the quantity and quality of early intervention services and further looked into the child and family factors that determined the continuation of services post diagnosis. This study is undertaken in New Jersey, USA. The study concluded that majority of the children received early intervention services before diagnosis and the services increased after diagnosis. Applied Behaviour Analysis (ABA) is the main early intervention approach used, however it was noted that a sub group of children did not receive ABA post diagnosis, with the only significant difference being a non-white race. Jane Braiden et al. (2012) evaluated a Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) based early intervention programme implemented by Barnados in Northern Ireland. 31 parents (18 female and 13 male) of preschool children (aged between two months to 3 years) with an autism diagnosis participated in the study. Parents reported reduces stress

levels and improvement in the child's receptive and expressive language skills after the implementation of this programme. This is a positive story of an evidence and practice based early intervention programme culminating in desirable outcomes.

Post diagnosis, currently there are a great number of intervention options for children with autism, including many empirically unsupported and controversial interventions (Metz, Mulick, & Butter, 2005; National Autism Center, 2009; Odom, Boyd, Hall, & Hume, 2010). In a cross national review of evidence based psycho social treatments published in psychology and education for children and adolescents with autism in UK, Ireland and United States, Robinson and Bond (2017) identified five main outcome focused interventions. The outcome foci can range from academic, communication, social, behavioural or multiple outcomes. These interventions were carried out in a school setting (main stream, special school, special education classroom in mainstream school) implemented by researchers or school psychologists. Evidence based interventions to achieve these outcomes include differential reinforcement, functional communication training, social stories, self management, cognitive behaviour therapy (CBI) and so on. The main new element in behaviour treatments concerns randomized controlled trials (RCTs) of relationship based preventative treatments for very young children (Rodgers and Wallace, 2011) of which Dawson's early start Denver Model (Dawson et al., 2010) and Green et al. (2010) parent mediated communication treatment (PACT) stand out. They both represent well designed and well undertaken RCTs, but neither has demonstrated results that shows a marked improvement in the core symptoms (Rutter, 2011). Chezan et al. (2017) document that behaviour based interventions were specifically used for children who displayed self injurious behaviours (SIB) like head banging, hair pulling and so on which further had a negative impact on the child's quality of life by development of friendship with peers, restricting community participation and developing health related problems. The authors note in their systematic review of twenty four studies that evaluated the interventions used to mitigate SIBs, albeit all evaluation

studies reported the interventions as effective, the studies did not have sufficient information to explain what percentage decrease, how consistent it was or the social validity (the intervention to continue) or procedural integrity of the intervention.

Whittingham et al. (2009) identifies a tendency for parents to generalise attributions about autism related behaviour to misbehaviour and it is argued that the parents has a tendency for the parent to attribute responsibility to themselves for autism related behaviour and misbehaviour.

From a pharmacological perspective, autism differs substantially from other mental conditions in the lack of benefits from medications with respect to core symptoms (McCracken, 2010). The most recent clinical finding which is of importance to children offered psychotropic drugs is that a significant weight gain is observed as a side effect compared to adults (Stigler et. al., 2004).

Another aspect of intervention is complementary health approaches (CHA). CHAs are developed outside of or parallel to mainstream medicine and may be categorized as natural products (e.g., herbal supplements), mind and body practices (e.g., yoga), or other approaches (e.g., special diets). CHA use is common among children with autism: between 28% and 95% are estimated to use CHA. Most CHAs have limited evidence of efficacy for autism (Lindly et al., 2017).

Rather than being guided by professionals (such as doctors in the case of medical conditions, for example), parents of children with autism are given a greater degree of freedom of choice in deciding the intervention and treatment options for their child (Valentine, 2010). Carlon et al., (2012) conducted a systematic review of the literature available on the decision making factors of parents of children with autism when choosing a treatment or intervention. Frequently nominated factors included recommendations from others (another parent or a medical doctor), the availability,

accessibility, and cost of interventions, the availability and use of other interventions, and research evidence.

From the perspective of this research study, the Scottish context in which this study is set is rich with diverse cultural demographics and it will be interesting to explore if race and ethnicity has a role in accessing or receiving autism interventions for their child that could further determine their quality of life. While a number of current interventions are well documented in literature, it is also worth exploring if the parents have mentioned any of these interventions being used in their child; if not why not. The data could shed some light on the Scottish parents' take on availability, accessibility and cost of interventions mentioned by Carlon et al.

To summarise, this section has outlined the contemporary thinking of autism as a concept and updates if any in the area of prevalence, diagnosis and interventions there by highlighting the area for knowledge generation through this research study. It is now time to move on to explore the current thinking in literature related to parenting a child with autism and the quality of life issues of the parents.

10.3 Parenting a child with autism

This section begins by summarising updates on child characteristics and behaviours shaping parent child interaction. The section then diversifies to summarise recent studies across the globe that looks in to the experiences of parenting a child with autism. The latter end of this section reviews recent studies that specifically commented on various aspects of the quality of life of parents of a child with autism .

10.3.1 Child characteristics and experiences of parenting

Autism Spectrum Disorder (autism) has lifelong implications for the functioning of the diagnosed child and his or her family. Highly replicated findings point to increased levels of parental stress in families raising children with autism (Dabrowska and Pisula, 2010; Hayes and Watson, 2013; Pozo

and Sarria, 2015), especially when the child shows behavior problems (Rezendes and Scarpa, 2011; Zaidman-Zait et al., 2014). Conversely, family adaptability influences the outcomes of individuals with autism (Baker et al., 2011).

Hong et al., (2017) did a meta analysis of the studies that looked at the functional living skills of children (adolescents) with autism. Functional living skills are defined as skills needed for being an independent individual in society. As individuals with autism get older, the discrepancy between the functional living skills of themselves and their peers increases. Given the lack of these skills, individuals with autism often tend to be dependent on their families or related services when they reach adulthood, resulting in an increased burden of care for their families or service providers (Howlin et al., 2004). For example, Shattuck and colleagues (2012) found that approximately 80% of young adults with autism lived at home, and among those individuals, only 6% had paid jobs after graduating from public schools. Brown et al. (2010) conducted a cross-sectional study of 97 families of school aged children with autistic conditions and argued that families of children with higher functional independence have lower unmet needs in terms of service provision (health, education, social care).

Rivard et al., (2014) conducted a Canadian based study on 118 fathers and 118 mothers of children with Autism Spectrum Disorder (autism) diagnosis to understand the determinants of stress utilising the Childhood Autism Rating Scale (CARS; Schopler et al., 1980), the Adaptive Behavior Assessment System-II (ABAS-II; Harrison and Oakland, 2003) and the Parenting Stress Index-Short Form (PSI/SF; Abidin, 1995). The findings highlighted that the stress levels of both parents were associated with their child's age, intellectual quotient, severity of autistic symptoms, and adaptive behaviours.

Hoogsteen and Woodgate (2013) did a Canadian based study about rural parenting experiences, especially parenting a child with autism. Twenty eight parents of children with autism (twenty six mothers and two fathers) participated in this qualitative study using phenomenological approach. The

diagnosis of autism became the focal point of the family and parents described how life slowly began to revolve around the child with autism. Parents were constantly having to carefully reflect and problem solve with respect to understanding their child's behaviours and needs. It was only through gaining an understanding of their child that parents were able to come up with the best plan in managing their child's needs. Every decision that parents made was affected by autism and it affected every choice that families made. From morning until the time that they went to bed, autism was present. Parents became so accustomed to life with autism that they did not realize all that they were doing to help their child flourish and become successful. While parenting a child with autism in a rural community, autism became centered within the family and parenting now included: (a) multiple roles (advocators, problem solvers, organizers, coaches, tutors, disciplinarians and primary caregivers); (b) an intense focus on their child's needs (it all revolves around kids approach ; and (c) finding a balance (taking breaks and seeking out support). Due to the overwhelming research involving mother participants and the limited father and spouse participation found in this study, future research including fathers and significant others is warranted. This is a significant gap in research which is also echoed by other studies (Nicholas et al., 2016) in literature.

Wang and Casillas (2013) describes the experiences of Mandarin-speaking immigrant parents, an understudied population, raising a child with autism in the United States. Using purposive sampling, semi-structured interviews were conducted with four sets of parents and two mothers of children with autism. Mandarin-speaking American families place great value in educational programs, express concerns regarding social stigma, and expect ongoing training and support (Parette et al., 2004). However, some mothers believe their child's disability may be attributed to the mother's failure to follow taboos or healthcare practices during pregnancy, or wrongdoings committed by the parents or their ancestors. m. For most parents, god/goddess or ancestor worship is their spiritual support. On the one hand, parents continue Western therapies (e.g. speech and/or behavior therapy)

for their children, but on the other hand, they follow folklore. Their child with autism became the center of their family life. Some were still struggling and trying to manage their stress, and yet some exhibited a much stronger family connection and sense of meaningful life mission. They were also searching for causal explanations of autism. In addition to the mothers' guilt that they might have violated certain traditional taboos or healthcare practices during pregnancy, parents also believed in genetics and/or environment/lifestyle. They also revealed that a child's better prognosis significantly relies on parents' devotion. Adhering to Chinese culture, these mothers valued family goals which outweighed personal goal and career success (Wang et al., 2013). The study provided limited qualitative information about the child characteristics or the role stereotyping and power dynamics of parents within the family setting. While the study highlighted the high expectations of parents for education interventions for their child, the findings did not paint a picture of their experiences in accessing interventions and support which can be pursued further in the current research study.

A similar qualitative study was done by Fox et al. (2016) on the UK Somali migrant parents settled in Bristol. 15 in depth interviews (12 females, 3 males) were completed with parents of children (less than 16 years of age) with a diagnosis of autism. For the Somali families in our study, cultural attitudes towards mental illness, challenging behaviour and disability, combined with the lack of vocabulary to describe and explain autism made the understanding and acceptance of their child's autism particularly difficult. Evidence suggests that mental illness is stigmatized in Somali culture and the existence of some conditions may even be denied altogether (Elmi, 2006). Parents in this study also reported that stigma related to mental health, challenging behaviour and disability reinforced families' tendency to hide their child and to avoid seeking help early. The findings indicate how bewildering it can be for migrant populations to understand and navigate unfamiliar health, education and social care systems, even for those who spoke fluent English. The language barrier was identified as especially pertinent to this problem. It also indicate that support is required to help

families to negotiate and navigate the health, social and educational services available to them during assessment, diagnosis and beyond.

The two studies within the migrant population in US and UK shed light on the cultural nuances in understanding autism and the stigma attached to having a child with a mental illness. However a common theme in both the studies is the uncertainties and difficulties in navigating the service and support systems within the respective countries they lived in. This is certainly another area which can be scrutinised in the data gathered to understand if the themes are recurring in the Scottish context.

Gill and Liamputtong (2009) did a small scale study looking at the lived motherhood experiences of mothers of children with autism in the Australian context. The findings of this study are thick and rich descriptions of mothers' perceptions of their role, their feelings, physical and mental health and experiencing stigma.

The literature also had a number of well documented quantitative studies that measured the parenting experiences using quality of life scales (WHO) , parenting stress index (PSI, Abidin, 1995) scales and a number of other scales depending on the areas explored. Findings on parental coping and parenting stress of parents of children with autism dominate the quantitative literature pool. Waikimizu et al. (2016) surveyed ninety three parents (78 mothers and 15 fathers) of children with developmental disabilities (term used to describe autism spectrum disorder in Japan) in central Japan. This study emphasized the roles of family empowerment and quality of life of parents rearing children with developmental disabilities in Japan. The participating parents generally had low scores for family empowerment and quality of life, high caregiver burden, and low emotional support network, self esteem, and self-efficacy. A summary of similar studies have also been documented in chapter 4.

What the literature highlights is the research community's interest to understand the parents' experiences across borders. While majority of the

studies are conducted in the United States, Middle Eastern Countries and Asian countries, there is a scope for a study based in the Scottish context as there is a paucity of research focusing on the Scottish population. Secondly, the literature update further reinforce that the studies looking at the quality of life experiences of the parents are based on pre determined scales and tools (WHOQOL, PSI). This was a theme that was emerging in the initial literature review completed in chapter 4. However, it is interesting to note that the research studies as recent as 2016 appear to follow the similar trajectory. While using scales and tools has its unique advantages, there is a scope for a study not utilising the prescribed tools to look at aspects that parents determine are important for their quality of life.

10.4 Quality of life aspects of parents of children with autism

As noted in chapter 4, there are various aspects of quality of life that is affected when parenting a child with autism. This section aims to update the literature review with most recent studies in this area.

10.4.1 Marital Relationship

The literature on autism-related parental adaptation recognizes the marital relationship as a primary source of support among married couples (Benson and Kersh 2011; Hartley et al., 2012).

In couples parenting children with autism, the partner becomes a primary source of emotional and instrumental support for addressing the additional parenting demands; thus, partner support should be seriously considered when helping parents adapt.

Different authors have found that parents of children with autism report lower dyadic consensus and lower levels of marital satisfaction compared with parents of typically developing children (Gau et al., 2012). In particular, Gau et al. (2012) found that mothers of children with autism reported more

psychopathology and marital dissatisfaction and lower levels of family cohesion and adaptability compared with mothers of children without autism. Furthermore, Hartley et al. (2010) reported that marital problems persist during the child's adolescence or young adulthood in families parenting children with autism.

Gracia-Lopez et al. (2016) conducted a study on 78 couples (fathers and mothers) in Barcelona. stress the importance of parents of children with autism to seek support from their partner to manage the everyday challenges related to their child with autism, such as receiving practical advice and empathic understanding. this study provides solid evidence of the actor and partner effects of supportive dyadic coping on relationship satisfaction and psychological adaptation.

Shur Fen-Gau et al. (2011) aimed to investigate the psychopathology, marital relationship, and family function in parents of children with autistic disorder (autism) as compared to parents of typically developing children. We also compared these measures between the mothers and the fathers. We assessed 151 families with at least one child with autistic disorder and 113 families of typically developing children in Taiwan. Both parents completed the self administered questionnaires measuring psychopathology, marital dyadic adjustment, and family function. Both parents of children with autism suffered from more psychopathology and less dyadic consensus than parents of typically developing children; mothers of children with autism, perceived less marital satisfaction, affection expression, family adaptability and cohesion than mothers of typically developing children. We also found that mothers of children with autism displayed more psychopathology and marital maladjustment than did the fathers. These findings highlight that parents of children with autism encounter more psychological problems, marital difficulties and family dysfunction, particularly their mothers.

10.4.2 Career

Watt and Wagner (2012) contributes to the literature on work-related factors for parents raising a child with a disability. Specifically, they used questionnaire methodology to compare two parent families raising a child with Autism Spectrum (AS) with similar families raising 'typical' children. Their findings suggested that parents raising a child with AS self-report higher parenting stress and more mental health symptomatology, as well as lower overall job satisfaction, less satisfaction with supervisors and less workplace contentment.

Caring alters plans to return to work and changes career trajectories for many primary caregivers of children with disabilities, most of whom are mothers. The "Juggling Work and Care" study (Crettenden et al., 2013) was a South Australian cross-sectional mail-out and online survey for carers of children and young adults with developmental disabilities aged 0–25 years, which investigated work participation, work–life balance and psychological well-being. This study shows that mothers who were in a couple relationship and primary caregivers for their child ($n = 287$) were less likely to be in paid employment and worked fewer hours than mothers in the general population, regardless of age of child. Work participation was shown to be strongly related to the severity of child disability. Impacts of caring for mothers were significant. Over a quarter of mothers who had intended to work after the birth of their child had not done so. As well, many mothers who had returned to work reported reduced job opportunities and career progression. Of concern, 9 out of 10 mothers were unaware of their right to request a change in working arrangements to assist them to care.

The literature also include evidence to indicate that impact on autism on career is a gendered issue. Baker and Drapela (2010) conducted a survey among single mothers ($n=326$) in Washington and Oregon who has a child with autism. Although both paid employment and parenting are widely understood as far from gender-neutral activities, negative employment effects become concentrated on mothers of children with autism.

10.4.3 Mental Health

Zablotsky et al. (2012) found that parents raising children with autism spectrum disorders (autism) experience high levels of stress and report a lower quality of life. The current study examined the association between child autism symptomatology, mother's quality of life, and mother's risk for depression in a sample of 1,110 mothers recruited from a web-based registry of families with children with an autism. Higher autism symptomatology and a greater number of co-occurring psychiatric disorders in the child were associated with an increased risk for current treatment of maternal depression and a lower maternal quality of life.

10.4.4 Remarks

The updated literature continues to highlight the stresses and strains of parenting a child with autism on the various quality of life domains of the parents. It will be interesting to see if parallels can be drawn in the findings of this research study focusing on Scottish parents.

10.5 Services (social work and other services) for children with autism and their families

There is a considerable history of conducting needs assessments by measuring perceived unmet need (Magi & Allander, 1981). This approach reflects the focus on consumerism in today's healthcare system (Wright et al., 1998) as well as the emphasis on family-centred care for children with developmental disabilities including autism (Kohler 1999; Sperry et al., 1999). Several studies have described the perceived unmet needs of families with a child with autism. Parents commonly report the need for information about available services as well as the need for information about how to handle their child's difficult behaviours (Granlund & Roll-Pettersson 2001; Ellis et al., 2002; McLennan et al., 2008). In one study, need for information was the most commonly indicated unmet need, reported by 47.1% of parents who had a 3- to 22-year-old child with autism, pervasive developmental

disorder or intellectual disability. Information was needed regarding teaching strategies, behaviour management and the availability of services (Ellis et al., 2002). To aid decision making regarding the allocation of limited resources, information is needed on the perceived unmet needs of parents of school-aged children with an autism spectrum disorder.

Brown et al. (2012) conducted a Canadian based cross-sectional survey w of 101 Canadian families of school-aged children with an autism to understand the unmet needs of school aged children and their families . Commonly reported unmet needs were for social activities for the child (78.2%), information about services (77.2%) and continuous service provision (74.3%).

Social support is an important factor in caregivers' capacity to cope with stressors (Lindblad et al., 2007). Social support includes psychological, physical, informational and material aid and is accessed from formal and informal sources by parents of children with autism (Boyd, 2002). Informal support includes support provided by someone in the individual's usual social network and is generally given in a voluntary capacity—most often by friends, family, neighbours or acquaintances (Boyd, 2002). Informal support is particularly valued by caregivers for providing emotional support (Lindblad et al., 2007). Formal support refers to support provided by an agency or organisation and may be privately or publicly funded but in either case the support-giver has a formal role and is usually paid for their assistance. Formal supports include family doctors, early intervention programmes and respite care providers. Families of children with autism draw on formal supports for information and professional guidance in managing the condition (Lindblad et al., 2005) and practical resources such as respite care.

Findings from the latest study conducted by Casagrande and Ingersoll (2017) lend support to previous research, which shows that children with autism utilize a high number of services (Gurney et al., 2006; Tregnago and Cheak-Zamora 2012), while simultaneously experiencing high levels of unmet needs (Chiri and Warfield 2012; Ruble et al., 2012). This study was

tailored around health care services. Service delivery outcomes in this population were further exacerbated by differences in parent education as expected. Less educated families reported receiving fewer services than more educated families and were less satisfied with the services they received. We found that less educated families also reported a higher number of needed services and lower overall adequacy (i.e., services received proportional to total service needs). We also examined whether parent empowerment or parent-professional partnership played a significant role in predicting service delivery outcomes. Both were independent predictors of service adequacy. However, while parent professional partnerships were related to service delivery outcomes as expected (i.e., with higher quality partnerships related to positive service delivery outcomes), the relationship between empowerment and those same outcomes was inverse to what would be expected—high levels of empowerment were related to poor service delivery outcomes in families of children with autism.

A New Zealand based study conducted by Searing et al. (2015) explored the perception of the availability and helpfulness of support for caregivers of children with autism in New Zealand, with subgroup analysis of the perceptions of Maori and Non-Maori; and rural and urban dwelling New Zealanders. Findings indicate that a wide range of formal and informal supports are perceived as available by most caregivers with preliminary indications that Maori perceive fewer supports are available than Non-Maori. No differences were found in the perceptions of support between rural and urban caregivers. While caregivers' partners and other parents of children with autism were perceived as very helpful the perceived helpfulness of formal support, particularly General Practitioner's and early intervention providers, were mediocre indicating considerable room for improvement in the quality of publicly funded services. Initiatives to improve professionals' knowledge of autism and the family-centeredness staff and services are indicated and specific suggestions are made.

Short breaks services developed in the late 1940s when disabled children were placed in hospitals to provide their families with 'relief care' (Oswin, 1984). By the 1970s, 'respite care' services developed within local authority social care settings, initially comprising residential services, but with the first family-based services appearing in 1979 (Stalker, 1996). A wide range of services now exists, managed by local authorities, health providers, voluntary bodies and within the private sector, providing residential, family- and community-based short breaks in a wide variety of ways to a wide spectrum of disabled children and their families.

Peerce (2009) illuminated literature with the 'Northampton model' of respite services for children with autism and their families outlining a range of key factors for consideration when commissioning short break services for children with autism. These are:

- the physical environment
- consistency between home, school and short breaks
- use of autism-appropriate approaches
- staff attributes, including their understanding of autism
- individualisation
- successfully accessing the community
- grouping of children

The 'Northamptonshire approach' is offered as an example of how short breaks have been provided in one local authority. What has been appropriate in Northamptonshire may be inappropriate elsewhere, and doubtless other routes of service development could have been followed.

Dyches et al. (2016) asked 122 single mothers to complete questionnaires concerning respite care, daily hassles (trouble) /uplifts (satisfaction, gladness), depression, and caregiver burden. More than half (59.8 %) accessed respite care, which was provided for one hour per day, often by multiple sources (41 %), such as grandparents and community agencies; most were satisfied with this care. Most mothers (77 %) had clinical

depression. Respite care was positively related to daily uplifts, and uplifts mediated the relationship between respite care and depression.

Rivard et al.(2015) examined how the parents of young children with autism spectrum disorders perceive the quality determinants of services provided to them in the context of a public network of services. Parents who suspect that their child could have an autism must first visit a primary care institution or a first line practitioner to obtain a diagnosis, a global assessment of their needs, and references to specialized services, as required. First line services also offer general psychosocial and medical services, support to the families, and autism specific (e.g., stimulation, support, information) services. Specialized services are offered by the second line of services, mainly through Rehabilitation Centers for Persons with Intellectual Disabilities or Pervasive Developmental Disorders (in French: CRDITED). These services include early behavioural intervention, social integration within different environments, information, and specialized support to families and collaborating agencies. Super specialized service needs are determined on the basis of the complexity and severity of the case, such as when severe co morbidity is present. The perceptions of 176 families who were receiving, or had received, specialized services for at least 12 months and were living in urban, suburban, and rural areas were investigated on three fronts: the relative importance of four determinants of quality, their degree of realization, and parents' satisfaction relative to these determinants. These determinants were the accessibility, continuity and flexibility of services, as well as the validity of information provided. Parents felt that the accessibility, continuity and flexibility of services were the most important determinants of quality. However, continuity and accessibility were also perceived as being the least realized. Parents were more satisfied with the validity of information and the flexibility of services than with their continuity and accessibility.

10.6 Remarks

Following the literature update, I have concluded that there continues to be a dearth in research studies that explored various aspects of the services streamlined by public bodies or statutory agencies (For example social work in the United Kingdom). Hence it further supports the rationale of this research study to explore aspects of the service delivery system that is mandated to offer support for 'children in need' (children with autism in this study) and their families.

Chapter 11: Discussion

11.1 Introduction

Using the iterative data analysis technique of grounded theory, 'Oppression' emerged as the overarching theory qualified by 'new normal', 'ongoing burden' and 'limited help' which contextualised the various aspects that parent participants considered important to describe their quality of life experience. The development of an overarching theory is the answer to the research problem which is: understanding the quality of life experiences of parents of children with autism. The aim of this chapter is to (a) place the grounded theory of 'oppression' in the wider context of existing theories in disability and quality of life research (b) discuss the implications of this theory on practice.

11.2 Where Does Oppression Sit in the Wider Quality of Life Literature?

An Internet search on QOL generates several hundreds of thousands of hits, which is indicative of the widespread use of this concept, of which many are confusing and at times contradictory. A quick skim of the literature on QOL reveals that the concept of 'quality of life' is understood by using various domains, and each set of domains covers major areas of life functions. However, different researchers choose to use different domains to describe QOL. For example, the WHO describes QOL using the following domains: physical health, psychological wellbeing, social relations and environment (Murphy et al., 2000). Schalock and Verdugo (2002) describe another widely used set of domains: emotional wellbeing, interpersonal relations, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion and rights. It is important to stress that the various domains used by different researchers have a large degree of commonality, even though they adopt 'different' terminologies. The WHO's QOL scale, the Health-related Quality of Life (HQOL) scale, the Family Quality of Life

measure (FQL) and the Parent Wellbeing Index (PWI) are some of the commonly used standardised tools in the literature to measure QOL.

To gain a better understanding of the place of 'oppression' in the wider literature, it is important to compare the findings of this study with the QOL literature. A careful review of the existing QOL literature focusing on parents of children with disabilities highlights the dominance of large-scale quantitative studies that attempt to 'measure' the QOL of these parents using single or multiple standardised scales (popular ones being the QOL scale of the WHO, Parenting Stress Index (PSI) and so on). A classic example of such a study is that of Dardas and Ahmad (2014), who examined the QOL of 184 parents (70 fathers and 114 mothers) of children with ASD in the Arab world. The study utilised multiple scales (the WHO QOL BREF scale, PSI and Way of Coping Checklist-Revised [WCC-R]) to measure QOL and found no significant differences between fathers and mothers in their physical, psychological, social or environmental health levels; their QOL was associated with parenting stress and coping strategies. A potential drawback in the study was the absence of a control group of parents (parents of children without disabilities or with other disabilities) to represent the general population.

Benjak et al. (2009) measured the subjective QOL of parents of children with ASD in Croatia using the PWI, employing as a control group, parents of children without disabilities. Parents of children with ASD reported significantly lower levels of subjective QOL than did the control group.

The concept of 'Oppression' as identified in the current study differs from the findings of the above two studies and other QOL studies of a similar nature in two fundamental ways:

Oppression 'describes' rather than measures the QOL experiences of parents.

Oppression refers to the internalised oppression experienced by the parents of children with autism.

This oppressive experience is characterised by impairment effects, barriers of being and barriers of doing (detailed in the next section), and gives meaning and depth to the researcher's curiosity: why do parents of children with autism who participate in quantitative studies have lower QOL scores? It also answers the first question of this research study: What does *quality of life* mean to the parents in this study?

Most QOL studies focusing on parents of children with autism and other developmental disabilities concentrate on mental health effects; evaluating factors such as parental stress, depression and psychological wellbeing (Bromley et al., 2004; Hastings et al., 2005; Johnson et al., 2011). They also focus on physical health, marital satisfaction and coping strategies (Allik, Larsson & Smedje, 2006; Knapp, 2004; Luther, Canham & Cureton, 2005). It is not surprising that the large-scale quantitative design in many of these studies stipulates the need for a control group or a comparative group (parents of children without disabilities or with other disabilities) to measure the QOL of the group under study. The point of interest for me here is the element of 'comparison'.

It appeared that the parents in the current study made constant comparisons of their personal experience to an 'internal reference' of what they perceived to be a normal or ideal QOL. This reference was heavily drawn from their own childhood experiences or what they saw in other parents with a child without disability or with other developmental disabilities. The point of internal reference (relating to other parents with a child without disability or a child with other developmental disabilities) was more explicitly used by the parents to articulate their difficulties and challenges in enjoying, for example, the social life to which they aspire (e.g., going on a holiday or attending a party); having 'me time' or family time with their partner/other siblings; or accessing vocational opportunities.

The following sections discuss 'oppression' in further detail.

11.3 'Oppression' from the Perspective of the Social–Relational Model of Disability

This study found evidence that several domains of parents' lives were affected by their child's autism and further identified that this was perpetuated by restrictive interaction between the parent and their environment (which includes child, family, community and social work services). This gave rise to the core category of 'Oppression' to summarise the QOL experiences of the parents in this study.

It is important to examine whether the child's autism was the sole trigger for this restricted QOL experience or whether it was a combination of the child's autism and other aspects of the parents' lives. This feeds into debate surrounding the question 'is disability medically induced or socially induced?' The medical model of disability argues that the 'problem' of disability occurs in the individual's body or in how the deviant body is perceived. According to the medical model, 'disability' is a health condition that must be dealt with by a medical professional and the person with the disability who needs treatment. Disability is seen as the problem of the individual and focuses on what the person cannot do. In other words, the condition or impairment creates limitations in the functioning of the person, which makes them disadvantaged in relation to others.

The social model argues that disability is a by-product of the restrictions placed on the individual by society. The British social model claims that disabled people are an oppressed social group. It distinguishes between the impairments that people have and the oppression they experience; most importantly, it defines 'disability' as social oppression, not a form of impairment (Shakespeare & Watson, 2002). Authors such as Oliver (1990) developed the traditional social model of disability, which conceptualises disability as occurring because of societal and environmental barriers driven by non-impaired values (values of people without any impairment), rather than disability being a direct consequence of physical impairments. If, for the sake of argument, I were to extrapolate from the social model of disability to

make sense of how their child's autism affected the parents' QOL experiences in this study, the QOL experiences summarised as 'new normal' were a consequence of the barriers that their child with autism experienced from society. This does not take into account the characteristics of autism that the child presents. However, the findings of this study disprove this.

While the accepted way to view and recognise disability and its subsequent effect on the QOL is through the lens of the social model as reinforced by the United Nations CRPD, this model does not acknowledge the role that a particular impairment or disability plays in restricting the activities of the individual and the family (Shakespeare & Watson, 2002). The latter argue that this is a great weakness in the social model of disability, because impairment is 'experientially ... salient to many'. That is, the social model encourages thinking in 'short hand', leading to the strong and popular proposition within British society that all restrictions in the QOL of people with disability and their families are caused by social barriers. The findings of this study offer evidence to substantiate this major criticism of the social model—that it fails to acknowledge limitations associated with the impairment (Crow, 1996; Shakespeare & Watson, 2002).

As part of reframing the social model of disability, Thomas (1999, 2004, 2007) persuasively argues for a social-relational definition of disablism. Thomas (2004) identifies impairment effects; that is, restrictions of activity that result from living with an impairment. This could include the fatigue or discomfort associated with some conditions, or the inability to do certain things. In addition to the effect of negative social interactions, it is important to take into account 'internalised oppression'. This refers to a person internalising the difficulties and challenges that come with the impairment or illness, resulting in them placing restrictions upon themselves (Reeve, 2012). Again, the focus of Thomas's social-relational model is the way disability is conceptualised. However, the current study approached the child's disability from a parent's perspective and examined how it makes sense for them in terms of their QOL. Irrespective of the differences in perspectives (from that

of a person with disability or of a parent of a child with disability), it can be argued that the concept of 'internalised oppression' reflected by the people with disability in Thomas's model is on a par with the oppressive or restrictive experiences verbalised by the parents in the current study because of their child's autism. While a person with impairment internalises the oppression they experience because of their impairments, the parents argued that the oppression they experienced because of their child's autism was a significant descriptor of their QOL experience.

Thomas (2004) further argues that there are two dimensions of social oppression that can disable people with impairments. First, disablement can arise in the interactions between people with and without impairment, affecting a person's self-esteem and psychological wellbeing, resulting in barriers at an internal, private level (Reeve, 2006; Thomas, 1999). For instance, negative social interactions such as hurtful comments or being stared at can result in a person with an impairment experiencing negative emotions and thoughts about themselves (Reeve, 2006). Thomas (1999) describes this form of oppression as 'barriers of being'. Second, in keeping with the traditional social model, environments can disable a person with impairment by excluding them (e.g., access to facilities and services), which Reeve (2012) refers to as 'structural disablism'. Thomas (1999) identifies this as 'barriers of doing'.

This study's findings promote the use of the social-relational model of disability to explain the role of the child's autism in an oppressive QOL experience of the parents. It further supports the argument of Crow (1996) that the social model of disability does not make provisions to adequately acknowledge the pain, unpredictability and helplessness experienced by parents. The social model therefore does not offer scope to acknowledge the personal experiences of parents. Having said that, there were findings in the study that acknowledged certain specific barriers ('barriers of being' and 'barriers of doing'); for example, community attitudes towards autism and the provision of social work services amplified the oppression that dominated the

parents' QOL experiences. Thus, it can be argued that the 'social–relational understanding' of disability proposed by Thomas (2004) explains 'Oppression' (QOL experiences of the parents in this study) using the three qualifiers 'impairment effects', 'barriers of being' and 'barriers of doing'.

11.4 Impairment Effects

In the social–relational model of disability, Thomas (2004) argues that 'impairment effects' mean that individuals internalise the negative effects of impairment, thereby imposing restrictions on themselves. What this means for the current study is that the child's autism imposed restrictions on the parents that dominated their QOL experience—an experience of oppression.

The parents in the study would have liked to believe that this oppressive experience was subjective and could not be appreciated or fully understood by anyone else. They were also of the view that their experiences were different from parents of children with other disabilities because of the hidden and complex nature of autism and its manifestations. They were of the view that their child with autism looked 'normal', and their 'disability was hidden' compared with children with learning disabilities, physical disabilities or sensory impairment. The findings suggested that the impairment effects of the child's autism pressured parents in many ways.

11.4.1 Dominating Narrative of Disability

Parents in this study acknowledged that they never contemplated having a child with disability, let alone autism. Nor did they have any first-hand experience of disability within their immediate family environment during their childhood years. This state of unpreparedness was reported by both male and female parents in the study. It contributed to the accelerated confusion and anxiety experienced by the parents when they began to sense that 'something was different' with their child. It has to be stressed that the changing presentation in the child was unforeseen and not expected. Autism appears to be unique in the way it begins to manifest in the child. Parents

reported a change in their development (no eye contact, loss of speech) that was irrecoverable.

One of the first critical points in the life of a parent is when they begin to ask questions like 'why is my child different?' Proponents of the neuro-diversity movement claim that autism is not a disorder to be cured; rather it is a human specificity or difference that involves different ways of socialising, communicating and sensing and that these differences must be respected (Jaarsma & Wellin, 2012). Neuro-diversity represents a shift away from psychoanalytic narratives of autistic disorder towards neurobiological and genetic accounts of difference (Ortega, 2009). The neuro-diversity movement thus goes beyond simply claiming rights and antidiscriminatory practices for neuro-diverse people, but argues for recognition and acceptance of difference. However, the parents in this study did not appear to view their child as neuro-diverse; at least not during the early manifestations of autism. Rather, the latter triggered a search for explanations. The male and female parents in this study experienced a state of helplessness because they were clearly not able to explain their feelings and thoughts about their child. 'Why me?' was an outcry in response to the sense of helplessness they experienced; however, the female parents chose to rationalise this further by searching for weakness in their interactions with the child. It was not surprising to see them blame themselves in desperation for an answer or an explanation for their child's state. Akkok (1996) conducted a Turkish-based quantitative study of the relationship between parental stress and causal attribution in parents of children with disabilities including autism. The variance in the stress of fathers was explained by the age of the child, the type of the child's disability, family characteristics and external blame (i.e., stereotypes of society), whereas the variance of mothers was explained by the type of the child's disability and 'bad luck'. Bad luck and external blame can be taken as factors that are difficult to modify and control by the parents and thus seem to be in line with the helplessness theory of depression (Alloy et al., 1988). 'Why me?' and 'self-blame' are irrational responses to the

parents' immediate circumstances, closely aligning with the 'theory of depression' (Alloy et al., 1988).

The attitude of the parents to blame or question themselves ('why me?') appears to be a harsh assessment of one's parenting abilities in a bid to explain the unexplainable changes in their child, which in turn altered the perceived 'normal interaction' between the parent and the child. This sense of self-induced worthlessness and helplessness was yet another manifestation of oppression that further dampened the QOL experiences of the parents.

The parents' search for an explanation often culminated in a discussion with a health or educational professional or a search on the web. It was in this search for a non-blameworthy explanation of their child's behaviour that the idea of disability was born. This is a common socially and culturally acceptable discourse to a presenting issue and to an extent helps divert the self-blame and parenting inadequacy propositions with which they have been struggling (O'Rielly & Lester, 2015). Lack of genetic and neurobiological explanations (Ortega, 2009) also fuelled the discourse that autism was a disability rather than a neuro-diverse existence.

Viewing autism through the lens of disability cemented the oppressive experience linked to the impairment effects of autism. It can be argued that the autism entered into the lives of the parents like a thief stealing away the normal parenting experience they previously had with their child. The 'vanishing skills' (loss of eye contact/speech) of the child was a blow to the parents because it robbed them of the normal parenting experience they thought they were having. It was anxiety-provoking for all parents in the study, who felt helpless and unsure. The 'vanishing skill effect' of autism left parents feeling deprived of the parenting experience they wished for. The expectations, sense of helplessness, confusion, anxiety and lack of preparedness expressed by the parents were early signs of how parents made sense of this impairment effect. Parents of either gender spoke about experiencing these internalised feelings primarily because of the

presentation of the child. This sense of deprivation can also be argued as an oppression that parents felt by not being able to be part of the parenting experience they desired or that they thought they initially had with their child with autism. Being deprived or robbed of a parenting experience they looked forward to was a setback in their QOL experience.

Getting a label for their child's presentation was important for all the parents in this study as it gave a categorical context to their oppressive experience. Studies by Rielly et al., (2017) and Avidi et al., (2000) report that getting an explanation of the child's presentation seem to be a priority for the parents with often the process of getting the label is followed by a grief process.

Expectations of what people with disabilities are and can be affect the lives of people with disabilities and their families (Green, 2007). Broberg (2010), analysing the life situation of parents of children with ID in a QOL context, argues that expectations of disabilities are often overlooked. In this Swedish-based research the parents had children with newly diagnosed ID. Watermeyer's (2007) tragedy discourse prevails in the findings of Broberg's study, with parents feeling bereaved and devastated. The lived experiences of the parents are seen as not static with respect to the emotions related to their child's disability, which appear to fluctuate over time.

Brogan & Knussen (2003) Banch et al., (2010) said that post diagnostic support plays an important role in assisting the parents to acknowledge their child's diagnosis and cope better amidst the process of grieving. However this study did not find evidence to indicate that the parents in this study had access to post diagnostic support that they found useful.

For parents in the present study, receiving an autism diagnosis served two purposes: it provided (1) a plausible explanation for an otherwise unexplainable presentation and (2) a starting point for services/interventions/search for help. Siklos & Kerns(2007) echo similar findings in their study.

The next section discusses further the impairment effects that characterised autism, creating an oppressive QOL for the parents in this study.

11.4.2 Visible or Invisible—it is Real

Several researchers (Dardas & Ahmad, 2014; Gray, 2002; Hoffman et al., 2008) exploring the correlation between the characteristics of the child with autism and parenting, parenting stress and QOL in general, either overlook the heterogeneity of autism as a spectrum disorder (with each condition on the spectrum having unique and varying degrees of similar characteristics) or fail to capture what living with a child with autism means on a day-to-day basis for parents. What most QOL research literature, including the studies mentioned above, indicates is that characteristics of the child with autism are associated with parents' QOL. For example, Wang et al. (2004) argue that the severity of the child's disability is a negative predictor of the parents' QOL. However, although these studies acknowledge that the child with autism has a difficult and challenging behavioural profile, they do not explain what this profile looks like. These studies highlight that autism affects the parents' QOL without necessarily stating how. The current study provided evidence to explain the specific challenges that autism brought to the lives of the parents.

Second, most QOL studies (e.g., Firth & Dryer, 2013) appear to focus on the link between the behavioural traits of the child with autism or other developmental disabilities, and the QOL of the parents. Although this research described the behavioural challenges in greater detail, an underlying finding was that autism is a hidden disability. That is, a child with autism looks normal, but does not meet the behavioural expectations of a normal child. Parents in this study argued that this disparity in the visual appearance and the behaviour of the child placed them in a more vulnerable and compromising position within their own extended family and society. Parents were of the view that society is more accommodating of parents of

children with other disabilities, such as learning or physical disability, because the disability of such children is evident or visible.

It may be useful to reflect on this point considering what response the parents would have if they had a choice to not have autism in their child's life. Based on the evidence found in this study, the answer to this question would be 'no'. The parents identified their child's autism as an inseparable change agent that instigated unsolicited changes in their QOL experience. Parents considered positive interactive experiences with their child as important for their QOL experience. While parents acknowledged that the entry of autism into their lives was unanticipated, they were left with no choice but to absorb the negative effects of their child's autism and carry on with their lives—their 'new normal'.

Of the several specific challenges identified in the study, the state of 'high alert' experienced by the parents was an important one to begin with. Parents were in a state of constant high alert because of the unpredictable nature of their child's behaviour and the safety concerns associated with it. This is also true for the parents of foetal alcohol spectrum disorder (Watson et al., 2013). Watson and colleagues also write about the anxieties and trauma expressed by children with ASD. In addition to the anxiety exhibited by the children, the parents in the current study spoke about being in a constant state of anxiety and stress, coded as 'high alert'. The unpredictable nature of their child's behaviours and the belief that their child was not able to ensure their own safety at any time appeared to place parents in a state of 'high alert'.

These findings are consistent with studies that indicate that maternal stress is related to the behavioural problems of children with ASD (Bromley et al., 2004; Hastings, 2003; Peters-Scheffer et al., 2012). However, the male parents in the current study also articulated a similar state of 'high alert' in relation to the safety of their child with autism. While safety of their child was the primary concern, the parents were also worried about the repercussions of their child's behaviour in environments over which they had limited or no

control (as in church or at the supermarket). They also battled with a sense of responsibility and guilt over the child's behaviours, yet they wished that the community or society as a whole were more accommodating and understanding of autism.

Parents of both genders acknowledged experiencing a sense of anxiety-induced alert state. This implied that the role of a parent was that of a 'protector', whose sole concern was the safety of the child. The parent-child interaction in this context was restrictive in focus and unidirectional in nature, with the parent attempting to have some form of interaction with their child through their protective response. However, the reactions from the child can be erratic, unpleasant or unpredictable. The QOL of the parents in respect to their role was reduced to that of a 'security guard' or caregiver ensuring both the physical and emotional safety (protecting the child from sarcasm, negative responses and attitudes from the community) of the child at all times. Several researchers (Dabrowska and Pisula, 2010; Hayes and Watson, 2013; Pozo and Sarria, 2015) report highly replicated findings of increased stress levels in parents of child/children with autism especially when the child shows behavior problems (Rezendes and Scarpa, 2011; Zaidman-Zait et al. 2014). The findings of this study support the argument of heightened parental stress levels; their child's autism related behaviour putting the resilience and coping threshold of parents to test. The build up (the behavioural issues are not described by the parents to be a one off) this experience is making their quality of lives restrictive and oppressive.

While threats to the physical safety of the child is related to the 'triad of impairments' (difficulty in imagination: e.g., no sense of danger), the emotional safety of the child was jeopardised by the attitude of the public towards a child with autism (barrier of being). Dillenburger et al. (2014) reports that the public have a reasonably good awareness of autism; if that is the case, this awareness has not translated into sensitivity and positive attitudes towards the needs of the child with autism, according to this study. Parents in the study experienced constant pressure to attach a 'running

commentary' explaining, clarifying and frequently apologising for their child's behaviour or mannerisms in any given situation. They often felt that they were harshly judged regarding their parenting capacity because people, more often than not, misinterpreted the 'behavioural challenges' of their child with autism as the 'tantrums of a misbehaving child' whose parents were not capable of managing them effectively. Parents felt demoralised and cornered by their child's autism and experienced varying levels of rejection, be it from their immediate family or from the community at large. This arguably was yet another dimension of the internalised oppression that parents experienced, which also painted a painful picture of a staggered QOL experience.

The parents in this study had been denied an inclusive and joyful interactive experience with their child, and had been subjected to emotional and psychological burnout because of the intense and draining role as a 'protector'. While 'high alert' emerged as one extreme of the impairment effect, the other extreme of the same was the 'lack of spontaneity' of the child with autism. The almost religious and ritualistic obsession with 'sameness' of the child with autism implied that pressure was on parents to adapt and mould themselves to accommodate the child's monotonously fascinated interests.

The male and female parents in the study appeared to adapt to this unique but ongoing impairment effect by making compromised choices to place the child with autism and the child's interests at centre stage. The parents' likes, dislikes, interests and wishes were pushed down the priority list. However, the study found that parents were frustrated with the constant prioritisation of their child's needs over their own, denying them what may appear to be the simple pleasures of life, like going out for a picnic on a sunny day. The findings indicate an elevated burden of care on the parents as noted by Howlin et al. (2004) who argued that children with autism had limited functional skills substantiating the need for ongoing and intense care from their families. This was an extremely oppressive state of existence for the

parents; arguably not one they would choose and not indicative of a QOL experience to which they would aspire.

While there is a predominance in the behavioural challenges presented by the child with autism in the QOL literature, a limited number of studies document how the physical health of the child with autism can affect the parents and is an important aspect of a positive QOL experience. This study found that in addition to the behavioural challenges of concern to the parents, other co-morbid conditions—for example, physical health conditions like anaphylaxis, bowel problems and dietary issues—amplified the difficulties of caring for a child with autism.

Yet another specific challenge of autism that floored the parents in this study was sleep difficulties of children with autism. Sleep difficulties were highlighted as another major behavioural challenge experienced by the parents in the study. Previous studies (Clements et al., 1986; Robinson & Richdale, 2004) document sleep issues such as co-sleeping, settling-in-sleep and night-walking for children with developmental disabilities. In this study, the parents—particularly female parents but also one or two male parents—highlighted the extreme sleep problems (including settling to sleep and co-sleeping) they experienced with their child with autism.

These findings reinforced that the obvious physical and mental exhaustion associated with providing care for a child with autism had a negative effect on the parents' QOL. Khanna et al. (2011) conducted an assessment of health-related QOL in the primary caregivers of children with ASDs. They found that female caregivers had significantly low scores for their physical and mental health. However, the current study found that physical and mental exhaustion reported by the parents was applicable to both genders. The demands placed on the parents were high and the role of the parent was more sophisticated (with expectations on parents to manage the child's sleep issues, have specialist knowledge about their diet and manage anaphylaxis). The female parent of one 14-year-old spoke about the persistent nature of her child's difficulties, resulting in the child having to share the bed and toilet

with her, even when going out for a day or two. The identity of the parent in this interaction was that of a caregiver who was expected to prioritise the demands and challenges of their child with autism.

Co-morbid conditions of autism appeared to restrict the physical and emotional functioning of the parents and they were trying to 'somehow' (as there were no clear solutions available to parents to manage these issues apart from an EpiPen for anaphylaxis) manage this challenging predicament and still make the space and time to execute other tasks as a parent/family member. Female parents in this study appeared to make compromises (e.g., go part time with their job) or give up their careers to meet these intense and ongoing demands. Although sleep issues were a common theme raised by the respondents in the study, the avenues for help and assistance to manage this were scattered and patchy. Therefore, the oppressive effects of caregiving (impairment effect) affected not only their physical and emotional wellbeing (areas identified by parents as important for a good QOL), but also their careers and the finances of the family (by losing out on the potential income of a family member), which again were strong indicators of the oppressive QOL experience.

Parents in this study argued that one of the defining impairment effects of autism distinguishing them from parents of children with other disabilities was that autism was a 'hidden disability'. They felt more disadvantaged than parents of children with other disabilities because their child with autism 'looks normal'. They were of the view that disability was better understood and comprehended by the extended family, informal social circle and larger community if impairment effects were visible and tangible, as in physical disability or sensory impairments. Parents believed that society was much more tolerant and accommodating of a child who 'looks disabled' than a child whose looks are normal but the effects of impairment are significant, which is the case for autism.

11.4.3 Summary

This study has brought a subjective and personalised angle to QOL research by providing evidence that a child's autism is a non-negotiable indicator for understanding the QOL experience of the parents. The findings argue that the parenting experience is oppressive due to impairment effects. It urges all interested parties to acknowledge that parents of a child with autism belong to an oppressed class and the impairment effects of autism dominate their QOL experience by making them feel oppressed. It also highlights that parents have limited choice and control over their QOL experience because of the dominating effect of their child's autism in their lives.

This study found that the role of parents was restricted to being a caregiver who was expected to be a protector and security guard, and to a provider who was expected to meet the child's physical and emotional needs without expecting anything in return. The parents categorically stated that autism reduced their QOL experience to a state of oppression.

11.5 Barriers of Being

The study found evidence that the oppressive experience of the parents' QOL went beyond the immediate experience of parenting their child with autism. It affected them at a personal and private level, imposing restrictions on their physical, emotional and social space. This was referred to as a barrier of being. In this section, I elaborate on the oppression experienced by the parents through exploitation by virtue of being a parent and courtesy stigma—the two main barriers of being in this study.

11.5.1 Exploitation by Virtue of Being a Parent

Exploitation is the action or fact of treating someone unfairly to benefit from them. In this study, the evidence suggested that parents felt powerless in their capacity to exist the way they would like to, to do what they wanted or to engage in what they liked. Their existence was closely intertwined with their child's autism. While the child with autism was benefiting from the care and

attention they received from their parents, this was to the detriment of the parents' QOL. In that sense, they felt exploited by virtue of being a parent. This action of unfairness precipitated in parents suffering in their physical, emotional and familial space.

Feeling contented emerged as an important aspect of the parents' sense of self. The Oxford Dictionary defines 'contentment as the state of happiness or satisfaction of an individual'. The threshold of contentment can be different for different people. Research often utilises life satisfaction scales and happiness scales to measure contentment. According to the parents in this study, feeling contented was important as far as their QOL experience was concerned. This research found evidence to suggest that parents were not contented with the status quo of their life. The status quo embodied the challenging experiences of parenting a child with autism. While parents in the study clearly articulated their commitment and responsibilities to their child with autism, they were also clear that if given a choice, they would wish their child not to have autism. Parental responsibilities in today's world often seem to include dealing with a child's behaviours, educational matters and other day-to-day needs of the child (Such & Walker, 2004). However, research clearly acknowledges that parenting a child with disability is more challenging than caring for a typically developing child (see Chapter 4 for details).

According to this study, parenting responsibilities primarily encompassed attending to the day-to-day needs of the child(ren) with autism (popularly known as 'caregiving') in addition to caring for the child's sibling(s) who were typically developing (for those parent respondents who had other children who were neuro-typical). Parents were of the view that autism impaired the ability of their child to learn skills for independent living such as toileting, bathing and using public transport. Parents voiced very strongly that their child with autism required ongoing and constant care to complete the activities of daily living. In their view, their child with autism required intensive input over prolonged periods to learn a new task. Even then, it could not be guaranteed that the child would master the task.

One male parent described his attempt to teach his son how to brush his teeth. The activity had to be broken down into several steps (1. take the toothbrush; 2. apply the toothpaste, 3; brush the teeth) and communicated to his son using an understood communication system. The constraints of not being able to have a verbal conversation increased the challenges of teaching this task. While this parent appeared to have a useful insight into his child's learning capacity and appropriate teaching strategies, this example provided insight into the specialist knowledge of their child's functioning that parents need to understand.

Parents stated that the stress of caregiving was exacerbated by the behavioural challenges (lack of sleep, being violent and aggressive, lack of insight into danger) and co-morbid conditions (anaphylaxis, bowel problems). Parents also spoke about accommodating numerous appointments with various professionals like psychologists, speech and language therapists and so on, which added to the stress of caregiving. Therefore, undertaking the parental responsibility of caring for a child with autism was a 'job in itself', leaving them physically and mentally exhausted. Parenting a child with autism placed a significant demand on them. Female parents continued to take the lead in the hands-on caregiving aspects, according to this study. This reinforces the findings of Hoffman et al. (2009) and Gray (2002) that mothers are often the primary caregivers of children with ASDs. If this is viewed in the context of a family, there are other competing demands that parents are trying to juggle. These include caring for other children and maintaining a career, social life and relationships with the extended family.

From a QOL perspective, it is important to ask: Do parents have any time for themselves? Not able to have self-care time or 'me time' as coded in this study was identified as a barrier. Parents, especially female parents, realised that a child with autism and the needs dictated by the child's condition took precedence. The expectation and demands placed on them were that of being a super human who would have to keep going without stopping. Parents in the study acknowledged that this was unsustainable, yet they

wondered what the alternative was. While they identified the need for 'me time', this was accompanied by emotions of guilt and worry: guilt that they had wished for time away from their child; and worry that their child's needs were best understood by them and they were irreplaceable. This worry stemmed from the child's limited capacity to communicate and their unpredictable acts that could place them, and those caring for them, in danger. For example, a male parent described an incident where he accompanied his son for a walk and suddenly his son decided to run to a nearby lake and jump into it. Parents felt pressured to not be off guard at any time ('high alert'). The physical (activities of daily living such as personal care, using public transport) and cognitive (being on high alert) demands of parenting a child with autism left little scope to even contemplate having 'me time'. Parents were disadvantaged because they believed that they were an 'irreplaceable' entity in the life of their child with autism. Parents were adapting to the needs of the child by sacrificing the needs of themselves. This was not a choice that they made; it was a necessity, definitely an experience with which they were not contented and one that clearly had psychological and emotional ramifications indicative of a devastating QOL experience.

The prolonged and intense caregiving as well as the behavioural and unpredictable challenges of the child with autism had an effect on the emotional health of both male and female parents. Although this finding is not supported by a statistical analysis, it endorses the findings of quantitative studies conducted by Abbeduto et al. (2004) and Magana and Smith (2006) that caring for a child with autism affects the mental health of caregivers. Mental or emotional health is a very broad term and can be interpreted in several ways. For parents in this study, it captured whether they experienced mental health issues at any point in their lives and whether their child's autism had a role in this. Anxiety and depression appeared to be the two main issues with which this group grappled, with the exception of one female parent who described substance dependence issues: primarily alcohol. It was a significant finding of this study that in addition to female parents, male

parents acknowledged experiencing mental health issues. The dearth of studies involving male parents reflects the fact that they are an under-researched group. It can be interpreted from the findings of this study that the child's autism played a pivotal part in the deterioration of the parents' mental health. While the stress associated with caregiving and the unpredictable and challenging behaviours of the child were the main triggers for female parents, male parents expressed their worry about the child's future and the pressure of being the lead or sole breadwinner of the family.

Zablostsky et al. (2012) has documented the negative effect of autism on maternal mental health. This study further identified that both male and female parents are being more vulnerable to mental health issues during the initial stages of coming to terms with their child's autism. Being in a state of high alert added to the emotional vulnerability of this group because autism appeared to make the child react in unpredictable ways, but often such actions were likely to be life threatening or dangerously close to their safety being compromised. Therefore, this study found that implications for emotional health were a barrier to feeling happy or satisfied and definitely did not favour a positive sense of self or QOL.

Hoogsteen and Woodgate (2013) mention that every decision that parents make are influenced by autism and autism affected every choice that they made. Evidence from the study suggested that both male and female parents fell short of time, energy and opportunities to have quality interaction with their other children, or share time together as a family. The unpredictable nature of the child with autism would imply that any family time they could potentially have must be planned and centred on the needs of their child. Hence, knowingly or unknowingly, the needs and wishes of other family members/siblings were bypassed through fear of unpleasant repercussions if the rhythm and routine of the child with autism was interrupted. Siblings of the child with autism could be classed as 'victims of autism' because parents often prioritised the needs of the child with autism over others.

Realistically, any family time with the child with autism would be restricted to the child's needs and interests; hence the choice and variety of activities they may choose to do as a family was limited. Any activity out of the autism box was more likely to be undertaken without the child with autism. Thus, it would be a rare scenario for the family of the child with autism to have an inclusive family experience with all family members present.

However, even if a family chose to engage in an activity or event without their child with autism, executing this would be difficult because parents in this study did not appear to approach friends and extended family (informal support) to share the caregiving responsibilities of their child with autism. This sits in tandem with the findings of QOL studies that argued that a poor support network (family and social) was associated with a negative QOL (Dardas & Ahmad, 2013b). The choice not to engage with informal support appeared to be a conscious decision as parents felt that someone who was not fully attuned to the day-to-day manifestation of the child's autism could not effectively manage their child. Parents were firm in their view that the unpredictability of autism was the hardest aspect to deal with and manage. Parents were worried that autism was a condition that could not be easily understood in comparison to physical or sensory disabilities, for example, where the impairment could be effectively managed with aids and adaptations. The reluctance of the parents to reach out to their family and friends was another indication of the restrictive and complex nature of autism. This implied that even in a hypothetical scenario of a family having a good informal support network, it was highly unlikely that this support would be called upon to manage the care of the child with autism.

Relationship issues were yet another barrier that made parents feel exploited. Kersh et al. (2006) studied the contribution of marital quality to the wellbeing of parents of children with developmental disabilities. They found that parents of both genders experienced low-quality marriages with mothers attributing this to the child's behaviour; in contrast, the fathers' dissatisfaction with their marriages was unrelated to their child's behaviours. In a similar

vein, the current study found evidence of stress and strain in the parent-partner relationships of both genders, attributed to the lack of time for each other. Parents also spoke about the feeling of 'can't be bothered for anything else'. Three female parents in the study explicitly stated that they separated from their partners because of their child's autism, which was evidence for an effect of autism on marital wellbeing. This study did not assume that parents of neuro-typical children do not have marital issues; however, what the findings highlighted was the possibility of having relationship issues between couples because of the child's autism. Parents who took part in the study were either single or living with their partner. Those parents who were single identified their child's autism as one of the many factors that led to separation from their partners. Those who continued in their relationships spoke about going through dark times in their relationship. A closer analysis indicated that the times when their relationships were shaky were times when as individuals they were trying to grapple with the child's autism. It was interesting to note that autism, projected as a barrier in couple relationships, was also identified by a couple of parents as a binding factor adding strength to their relationships.

A female parent spoke about having a non-existent sex life. Dealing with the child's autism not only restricted the time they had to share with their partner, but it also appeared to make them exhausted and tired, such that parents were unable to accommodate their partners' needs. Enjoying a quality relationship with their partner was an important element of their QOL, but a quality relationship needed time commitment and opportunities to be together. This was not happening, according to this study. Parents were deprived of the pleasurable experiences of being together as a couple and were restricted with what they could do to maintain and enjoy their relationship. This suggested that their role as a husband or wife was no longer prominent in their lives because their identity as the mother or father of a child with autism was more pronounced. The disappointment and frustration as a partner was submerged in the responses and responsibilities to their child with autism. Thus, relationship issues were yet another barrier

that prevented parents from maintaining the relationship that they aspired to with their partner. The dissatisfaction in their capacity to share a quality relationship spoke of a dissatisfied QOL experience. These findings concur with the lower dyadic consensus and lower levels of marital satisfaction as reported in literature (Brobst et al., 2009; Gau et al., 2012; Higgins et al., 2005).

11.5.2 Courtesy Stigma

Stigma is what occurs when society degrades or loses respect for a person because of some unique attribute or characteristic that is seen as undesirable. Courtesy stigma is 'stigma by association'. The idea was first introduced in 1963 by sociologist Erving Goffman. In his book, *Stigma: Notes on the Management of Spoiled Identity*, Goffman describes courtesy stigma as society degrading or losing respect for a person because the person associates with someone who is stigmatised.

This study identified parents isolating themselves socially, particularly because of the fear of courtesy stigma. Attending family events or community events that could be considered an innocuous routine for a 'normal family' could be a stressor for the family of the child with autism. This is because the child was being taken to an environment with which they were not familiar; hence the chance for the child to behave in an unpredictable and unwarranted manner were high. It could be embarrassing and stressful for the parents to be in such a situation. It might also be a painful experience to watch any potential unpleasant responses to their child's behaviour. While it could be argued that people in the extended family and community must make reasonable exemptions for the behaviour of a child, the child with autism can engage in extreme behaviours (e.g., making loud noises, playing with fire) that could compromise the safety of the child as well as others. There were some exceptions in this study in which the extended family were more accommodating of the child with autism irrespective of their extreme behaviours (e.g., urinating on the carpet during visits to the extended family).

What emerging from this was the challenges of stigma experienced by the parents that interfered with their aspirations of having family or social time in a way they desired; the difficulty of participating in conversations or activities with other children and the inability to participate in family events or activities or plan outings as they desire. In short, it could be argued that the wellbeing of the parents was affected by courtesy stigma, which again was indicative of a QOL experience that was oppressive.

Witcher (2003) argues that social exclusion is a complex phenomenon with roots in social, political, cultural and economic structures. The disciplines of sociology and anthropology are built on the basic tenet that human beings are social animals. This means that co-existence, interaction and association with fellow human beings are expected to be a natural part of human lives. Fellow human beings can include immediate family, extended family, friends, colleagues, community and so on. Several researchers (e.g., Dobson et al., 2001; White et al., 2003) flag the recurring theme of social isolation and loss of social opportunities in parents' lives. Data gathered in this study indicated that both male and female parents had restricted social participation. The desire for social interaction can be different for different parents. Some parents may like to maintain intense and frequent interaction, while others may prefer to socialise once a week or once a fortnight. This may depend on their circumstances and various other factors. Although the nature and extent of social interaction sought may be different for different parents, it was acknowledged that parents identified spending time with family, friends, colleagues or community as an essential component of their QOL.

This study identified several barriers contributing to courtesy stigma. Parents were of the view that the challenges presented by the child with autism were major. The triad of impairments of autism made it difficult for the child to interact and communicate with others. The child appeared to function better in environments that were familiar and predictable. Unfamiliarity or change in routines made the child anxious and this anxiety might be displayed through externalising behaviours like flapping, making high-pitched noises, throwing

tantrums, urinating in public and so on. A socialising environment (e.g., at a barbecue, park, café or homes of friends and family) as unpredictable for the child and might include stimulation (different people attempting to communicate with the child, children running around and so on) that could trigger extreme reactions from the child (screaming, rocking, flapping). Parents felt the need to be on 'high alert', watching the child constantly, which took away from the purpose of relaxing and enjoying interaction with others.

The barriers presented by autism made parents feel uncomfortable and responsible for the perceived inconvenience caused by their child's presentation. There was also a sense that people may choose to avoid extending invitations to gatherings because of their child's autism. One parent spoke about how their other children were not invited to birthday parties or sleepovers because of the concern that their autistic brother or sister may turn up.

Yet another barrier that contributed to courtesy stigma was the restricted ability to making spontaneous plans with friends or family. This inflexibility was linked to the lack of spontaneity of the child because of their autism. It also impeded the parents' ability to make plans for holidays, as the likelihood of encountering scenarios and circumstances that were unfamiliar to the child with autism was very high. This suggested that parents would end up managing the repercussions manifested through their child's behaviours, defeating the purpose of having a holiday. Hence, the potential for experiencing courtesy stigma was high.

11.5.3 Summary

To summarise, this study gathered evidence to substantiate that the research participants were exploited by virtue of being a parent and by courtesy stigma. In the context of this study, this included those aspects (need for 'me time', issues with emotional health and relationships) that made parents feel discontented with their life. It also encompassed the

limited opportunities and restrictions experienced by parents to ensure optimal participation with the family, and in their social life. These 'barriers of being' magnified the oppressive experience that summed up their QOL.

11.6 Barriers of Doing

Barriers of doing are physical, economic, material or structural barriers that restrict or prevent people from doing an activity. This study found evidence for the following two elements of barriers of doing that contributed to the QOL experiences of parents being akin to oppression: 'less human' and 'marginalisation'.

11.6.1 Less Human

In the context of this study, it was described as stemming from the unintentional behaviour of the child with autism and society that reduced the potential for the parent participants to be fully human; to put it another way, actions and behaviours that made them feel 'less human'.

Traditionally, studies conducted on families with a child with autism examine the interaction by concentrating on the effects parents have on the child, not the child's effects on parents (Kanner, 1943). Also, the majority of QOL studies on autism focus on the mother–child relationship and do not include an analysis of the father (Gill & Harris, 1991; Gray, 2002). This study found that the child's autism affected parents of both genders.

The 'less human' experience was further qualified by the quality, or lack of quality, of the parent–child interaction. This was perpetuated by the child's autistic traits that closely aligned with the 'triad of impairments of autism' (difficulties in social interaction, social communication and social imagination). Parents of both genders identified that the lack of quality in the interaction with their child with autism was a significant qualifier of their QOL experience. Markus et al. (2000) argue that the evidence regarding the relationship between autism severity and parent–child interactions is limited. This study found evidence to indicate that a child's autism raised barriers in

the quality of interactions the parents had with their child. Parents were of the view that they were denied the normal parenting experience to which they aspired because autism had an obscuring effect on communication, interaction and, more importantly, attachment between parents and the child. Parents of both genders highlighted that attempted conversations with their child were primarily 'one way'. This was attributed to the child's limited verbal communication skills. While a few parents explored alternative communication systems such as PECS and SIGN, these communication experiences were reported as feeling pre-emptive and staged. They did not consider this to be natural; rather, it was atypical or oppressive. The parents' QOL was again affected because they were deprived of the opportunity to have a conversation with their child, which made them feel 'less human'.

Yet another important aspect of parent-child interaction is attachment. An interesting gender difference found in this study was that female parents yearned for an emotional, warm and intense interaction with their child with autism, which in their view was not reciprocated by their child. The experience of a cold response from their child was so intense that one parent in the study used the metaphor 'dead child' to describe the frustration and pain of being emotionally 'out of sync' with her child. According to this study, the male parents' approach to building attachment with their child was through play. However, they believed that the child struggled to comprehend the rules of the game or the spirit of sport. Parents attributed troughs in the interpersonal dynamics with their child to the interaction and imagination difficulties associated with autism. These findings contradicted Koren-Karie et al.'s (2009) argument that secure attachment for children with autism is not related to the severity of autism but to greater parental sensitivity and developmental competencies. They also highlighted that not having the quality interaction they desired with their child with autism fostered the feeling of being less human. To summarise, Kanner (1943) reports that a characteristic feature of autism is how the child relates to others, including strangers and those with whom they share an enduring relationship (parents). The loss of quality moment-to-moment social interactions and

interpersonal engagement between participant parents and their children with autism was also established as a significant oppressive experience that downgraded their QOL experience.

The attitudes of the community were another barrier that cornered the parents into feeling less human. Parents spoke about experiencing hostility and intolerance regarding their child's behaviour from the community. These judgmental reactions could range from being stared at, to rude and cold responses. Parents felt that this unpleasant attitude from the community was significantly linked to the hidden nature of their child's autism. It was the perception of the research respondents that society is more accommodating and tolerant of people with physical disabilities, sensory impairment or other developmental disabilities where the disability is reflected in their physical appearance. In the case of autism, parents stated that the child looks 'normal' and hence the expectation of society for the child to comply with the norms and etiquette of social existence is similar to that for people with no impairment or disability. Parents were of the view that when these children are young, society is more inclined to ignore their unacceptable behaviours, such as tantrum. However, when the same child presents with similar behaviours when they are older this places parents in a more compromised position where their parental capacity is subjected to judgment by the society. Although parents were able to appreciate the lack of understanding of autism by the community, this did not remove the hurtful and painful memories they retained because of these belittling attitudes towards them and their child.

11.6.2 Marginalisation

Marginalisation may be described as the confining of people to a lower social standing. It is a process of exclusion that not only effectively positions certain groups as 'inferior' within society, but also makes that group largely 'invisible' within society.

The parent respondents in this study identified that the restrictions experienced by them in pursuing a career/vocation made them feel marginalised. Despite the existence of the *Equality Act 2010* and a number of laws and policies to support parent-carers, having a career when parenting a child with autism was challenging, to say the least.

A study by Contact a Family (2004a) reports that 32% of parents of children with complex health needs have problems at work. A subsequent study (Contact a Family, 2004b) identifies several specific issues reported by parents, which relate to:

access to appropriate childcare

after school and during school holidays

time needed for hospital and school appointments, and reviews

lack of understanding and flexibility on the part of their employers.

Hewitt-Taylor (2007) report that parents in their study identified a need for flexible and part-time job opportunities. However, the same parents also acknowledged that they were limited in terms of the hours they were available for work and by their own lack of flexibility.

Having a career or being employed ranked high on the participant parents' wish list for retaining a positive sense of self and therefore a good QOL. However, predominantly female parents gave up their careers or reduced their working hours to accommodate the responsibilities of caring for a child with autism. What this reinforces from a QOL perspective is that female parents have had to sacrifice their aspirations for a successful career. With the exception of two female parents who worked part time, female parents in this study had resigned their jobs or given up their careers. This could be attributed to the lack of sleep experienced by the female parents because of the sleeping challenges posed by the child. The stress associated with supporting their child with their activities of daily living and accompanying them to medical and other appointments could also impede their capacity to

be available for work. Female parents also spoke about frequent interruptions at work by the child's school because of behavioural issues. They felt pressured to be 'on call' to respond to their child as and when required.

This unpredictability associated with the needs of the child could also have contributed to female parents' decisions to not work. The guilt of having to request frequent time off work to cater to the needs of the child (such as attending ongoing appointments with professionals) was relayed by parents who made the decision to resign. This implied that the restrictions placed on the female parent because of caring for her child with autism affected her availability to work. Female parents appeared to deal with this either by resenting the fact that they could not work or by accepting it painfully. This gesture on one hand reinforced the female parents' commitment to the care of their child, but on the other, reflected the barriers faced by them that prevented them optimising their employment potential. This was a clear step backwards in their sense of worth and their QOL.

Male parents, however, felt restricted in contemplating career progression or job change. Watt and Wagner (2012) has reported lower overall job satisfaction in parents of children with autism. This was because they either shared the hands-on responsibilities of caring for their child, which gave them limited flexibility, or they were anxious about upsetting the rhythm of the family, especially their child with autism who liked predictability and sameness. Lack of spontaneity, one of the pressing challenges associated with autism according to this study, could be undermining the career choices made or, more importantly, not made by them. Three male parents in the study were unemployed. While one of them was looking for work, the remaining two made the choice to share equal caring responsibilities with their partners.

The majority who worked were the main or sole breadwinner of their family. They often worried about the financial security of the family and the future of the child with autism. They carried the pressure of bringing in the money and

keeping the household running as female parents led on the hands-on caring of the child with autism. Crettenden et al. (2013) argued that female parents who are in a couple relationship and have the primary care giving responsibility of their child with autism were less likely to be in paid employment or worked part time hours. This is supported by the findings of this study.

Nonetheless, the male parents described the overwhelming exhaustion of returning from work to the autism household and immediately stepping in to care for their child with autism to give their partner a break. In other words, the male parents, like their female counterparts, were fighting physical and mental exhaustion. This could interfere with their work quality and output in the long run and the potential to follow their career dreams.

From a QOL perspective, autism was a strong influence when it came to the male parents making vocational choices. For those who chose to continue to work, the monetary burden of the household lay with them and the pressure was on to keep going. With autism came the inflexibility to make career changes or progression, as any change was weighed against the risk of upsetting the familiar and predictable routine that as central to the wellbeing of the autism household. Hence, autism did pose a barrier in the working lives of both the male and female parents and their career aspirations that were critical in lowering their sense of self. This also pointed to an unsatisfactory QOL because they felt discriminated against or marginalised because of their child's autism.

This study also examined one of the important structures of help in the socio-political framework of Scotland: social work services. The data indicated that a lack of effective services from social work pushed parents further to the invisible corners of society, making them feel marginalised.

According to this study, female parents, in contrast to their male counterparts, took the lead in making contact and negotiating for help with social work. Assistance allowing them take a break from caring for their child

with autism appeared to be the main social work request made by parents. From the above discussions, it is clear that parents made an intrinsic connection between their QOL and having 'me time' to have a rest, as well as 'family time' to spend one on one with their other children. Parents who received social work services were appreciative of what they were offered but were of the view that it was too little too late. Cagran et al. (2011) speak about the lack of effective connection between parents and social services negatively affecting parents' QOL.

One of the main barriers that made them feel marginalised was the difficulty in receiving real-time help; that is, receiving help at the time of need. Peerce (2009) and Dyches et al. (2013) has outlined the importance on autism friendly and timely short breaks to uplift parental quality of life. Parents spoke about the frustration of contacting social work and the sporadic and patchy responses they received. The study found that two of the study local authorities worked towards service standards for response; that is, completing an initial assessment visit within two weeks of making contact and within approximately three to six months, allocating a worker and completing an assessment to ascertain areas of help. Although it was beyond the scope of this study to understand whether these service standards were met, parents were not satisfied with the time taken from when they first made contact with social work to when they were able to access help. However, social workers were of the view that parents should be making contact with them prior to reaching crisis and should be appreciative of the processes involved in streamlining help for the family. What can be concluded from this is that there is a disparity in the expectations of parents and social workers, especially around time frames of service delivery. What parents considered beneficial for their QOL was the opportunity to access assistance in a timely manner. What this study found was that parents expected social work services to be more proactive and sensitive to their circumstances and to take the lead in delivering the assistance rather than placing the onus on parents to push for help via constant follow ups with social work. Brookman-Frazee (2009) reports that

collaborative partnerships between parents and professionals often result in positive outcomes for the child and the family QOL. However, the current study did not report a positive collaborative partnership between parents and social workers; in fact it highlighted their differing perspectives and expectations.

I found no information available in the public domain to indicate that a review of the current service standards used by the study local authorities has been undertaken to understand whether service standards are being met and whether the current service standards are on par with the expectations of the service recipients, which include the parents.

The relative newness of autism in the social work services remit and the uncertainty surrounding the assessment and management of autism provided further explanations for the marginalised experiences of the parents. There was a perception among the participants in the study that there was an increase in demand for social work services for children with autism and their families. Although this did not appear to be based on statistical evidence, this was a popular view of the social workers and the operational managers who participated in the study. None of the study local authorities appeared to have statistical evidence of the percentage of children and adults diagnosed with autism within their local authority area. One way to interpret this increase in demand is to consider autism as a relatively new entrant in the disability cohort to which social work services cater. This was substantiated by parents' accounts of social workers not demonstrating a good understanding of the specificities of the condition, therefore being unable to build trust and confidence with parents. Parents were of the view that they themselves were expected to be experts in autism, which they were not; however, they were pressured to become so because the professionals did not demonstrate expertise and confidence in the field of autism. Social workers also acknowledged their lack of professional confidence in dealing with autism and the general sense of ambiguity surrounding autism. This could be interpreted as not meeting the code of

practice of the SSSC (2014), which stipulates that 'as a social service worker, you must uphold public trust and confidence in social services' or simply seen as a barrier to offering parents services that would have a positive effect on their QOL.

The ambiguity around autism in the social work world opens the gate for a discussion around the question, Does autism require specialist intervention from providers who specialise in autism? Another way to ask this question is, How is autism approached from the perspective of assessment and commissioning of services for child with autism and their parents? The *Scottish Strategy for Autism* (2011, p 21) posits autism as a lifelong condition that presents with a range of complex needs that may include learning disability and mental health issues. The current study found that services were more easily available when autism coexisted with a learning disability. It appeared from the findings of this study that parents were in a better position for receiving a service from social work if their child had a diagnosis of autism that was compounded by a diagnosis of learning disability, as conventional providers of disability were established in the field of learning disability. This also implied that, irrespective of whether autism was the primary diagnosis, the co-presentation of learning disability was the key to gaining access to the service providers through social work. It was viewed that the case was similar to accessing input from community learning disability nurses whose services were restricted to clients with a diagnosed learning disability. I am inclined to question the specific needs of autism being side-lined in this and the necessity to fit autism into the box of learning disability services. Is this where a call for a specialist provider for autism is coming from?

The study found no evidence to support an argument for the need to have a specialist autism service to improve the QOL of children with autism and their families. There was insufficient evidence suggesting any specific input that specialist service providers for autism in the community could bring to the table. One study local authority gave respite vouchers to parents to source

respite from an autism charity. Parents said that when this charity was contacted, they often sent university students who had an interest in autism to assist them with their child with autism. The call for a specialist service might stem from a few factors such as the lack of knowledge base of the social workers to understand the specific needs of autism and the difficulty in establishing the trust and confidence of the parents. However, parents were not satisfied with the information made available to them regarding the options for help. Therefore, a specialist service that advertises itself well has a better chance of capturing the attention of parents in desperate need of help than do social workers who are unsure of what is best for the child with autism and their families. It can be concluded that the existing provisions of help from social work were not adequate to make parents feel supported in their pursuit of bettering their QOL.

What did emerge from the study was an argument for autism-inclusive help where the specific needs of autism are assessed like any other disability and services/help are commissioned to meet those specific needs. The lack of professional confidence to do justice to their needs assessment and the ambiguity of where autism would fit within the existing service provision could be precipitating the oppressive experience that parents encounter when interacting with social work departments. This also raised questions about the effectiveness of the implementation of the commissioning guidance provided by the Scottish Government to local authorities (Audit Scotland, 2012) to improve the QOL of parents. Having said that, this has been put in perspective by the changing landscape of social work and health services driven by the *Public Bodies (Joint working) (Scotland) Act 2014*.

Parents in this study also spoke about the need for flexible and dependable options for respite to ensure that they got a regular break and had quality family time with their partners and other children. Given autism is a condition that thrives better with familiarity and predictability, parents were keen to explore whether respite could be offered in the most familiar environment, namely the home environment. Hunter and Ritchie (2007) discuss

coproduction and personalisation of social care as the recommended pathway for social work to develop collaborative and customised outcomes for children with autism and their families. Personalisation and SDS (www.selfdirectedsupportscotland.org.uk, accessed on 12 February 2015) is the Scottish Government's answer to ensuring that children with autism and their families have a better QOL experience and have choice and control in shaping the services that meet their needs. Even before the introduction of the *Self-Directed Support Bill* in 2012, local authorities had the option to offer direct payments to parents, giving them the flexibility to plan help in a way that worked best for them. However, the study did not find evidence to suggest that direct payments were a popular choice among the parents. Although parents were of the view that direct payments were not offered to them, social workers stated that parents were often not keen to take up direct payments because of the responsibility, formalities and processes involved in employing and managing a personal assistant or a service that would assist them with their child with autism.

Finally, the *Community Care and Health (Scotland) Act 2002* affirms that carers who intend to or provide a 'substantial amount of care on a regular basis' are entitled to an assessment of their ability to provide or to continue to provide care (carer's assessment), independent of any assessment of the person for whom they care. The legal definition of a carer is someone who provides substantial amounts of care on a regular basis for either an adult or a child, where that adult or child receives, or is eligible to receive, support services under the *Social Work (Scotland) Act 1968* or the *Children (Scotland) Act 1995*. A carer is generally defined as a person of any age who provides unpaid help and support to a relative, friend or neighbour who cannot manage to live independently without the carer's help because of frailty, illness, disability or addiction.

In the context of this study, it was established that parents, primarily female parents, would meet the criteria of 'carer' and hence were eligible for a carer's assessment. One of the purposes of the carer's assessment was to

determine what the carer needed to maintain and improve their own health and wellbeing (Scottish Government, 2015). In other words, the purpose of the carer's assessment could be interpreted in the context of this study as how best could a parent be supported to improve their QOL experience. The study found that parents and often social workers were confused and unsure of what a carer's assessment was and what they would achieve by completing one. Social workers reported that the uptake of a carer's assessment was not high because the completion of the assessment in itself did not guarantee an outcome that the parents viewed as beneficial in improving their QOL. Social workers who had completed carer's assessments often did so to add weight to the Section 23 assessment (children in need assessment in accordance with the *Children (Scotland) Act 1995*) to optimise the chances of getting funding to commission services for the child with autism and their families. There was also a view among the social workers that there was an overlap in the Section 23 assessments and carer's assessments, indicating a sense of unnecessary duplication in the assessment process.

11.6.3 Summary

Parents in this study felt less human and marginalised because of the significant gaps between aspirations in the Scottish political and legal framework (developed in the best interest of the country's citizens) and the reality on the ground. This contributed to parent respondents experiencing a QOL of oppression.

11.7 Key Learning of this Study

According to this research study, any venture that focuses on optimising the QOL experiences of the parents of children with autism should:

acknowledge the dissatisfaction or gap between the inspirational QOL and the oppressive QOL

identify that impairment effects continue to emerge as the most significant explanatory link in terms of this oppressive QOL experience

understand the vulnerability of male and female parents as evidenced by their desperation for a break, propensity for mental health issues, relationship breakdown, lack of family time, limited vocational flexibility and social isolation and the lack of support network (be it universal services, leisure services or extended family)

understand autism rules: fragmentation of family time, guilt about neglecting other children and those children not having a normal parenting experience

appreciate that parents feel pressured to be experts because of the hidden nature of the disability placing an obligation/expectation on them to constantly explain the needs and behaviours of the child

recognise the reality that caring for a child with autism is prolonged, intensive and exhausting

acknowledge that parents, especially female parents, experience resentment because of their limited capacity to make contributions to society either from a, economic perspective or by making themselves available to participate in community activities; this study also identified that the skills and training of parents (especially female parents) are underutilised because of their inability to access vocational opportunities

recognise that social barriers like community attitudes; inadequate universal services and leisure options; and lack of extended family support also contribute to 'Oppression'.

The findings of this study urge social work professionals and planners to acknowledge that any attempt to improve the QOL experiences of the parents will require:

delivering help within a time frame that parents find useful

that social work be more proactive rather than reactive in offering help

a scoping exercise to estimate the exact numbers of children diagnosed with autism in the study local authorities, which will be beneficial in planning and service delivery

offers of flexible and dependable options of respite

keeping parents informed of all the services that may be available to them

social work professionals embracing autism like any other disability and being trained to expand their knowledge and skill base

building trust and confidence in parents by demonstrating understanding of autism and coordinating the services accessed by the child with autism

developing the conventional framework of disability service provision to incorporate the needs of individuals with autism; in other words, offering autism-inclusive help rather than specialist help

offering step-by-step guidance and advice to parents in relation to accessing SDS

clarifying the goals of undertaking a carer's assessment.

11.8 Conclusion

To conclude, it is my argument that the QOL experience of the parents of children with autism in this study was that of oppression. The oppressive QOL experience is characterised by impairment effects, barriers of being and barriers of doing.

11.9 Implications of the Study

I now reflect on the implications of the findings in this thesis for education, practice and future research.

11.9.1 Implications for Education

This thesis has examined QOL experiences predominantly from a parent's perspective. The theory of 'Oppression' developed in this research shed light on normalisation of autism in the lives of parents. The education of parents of children with autism, especially those whose children were in the initial stages of autism and who were trying to make sense of this new world and its effect on them, was an initial implication of this theory. This theory can also make a valuable contribution to the continuing professional development and training of social workers, particularly those who are working in the field of disability. Training sessions developed using the theory 'oppression' might also be targeted to sensitise disability support workers and respite workers who are anticipated to have frequent interactions with children with autism and their parents. The categories 'new normal', 'ongoing burden' and 'limited help' spell out the restrictions experienced by parents in their QOL on two levels: as a parent and as an individual.

At the parent level, this thesis substantiates that living with a child with autism is not a normal parenting experience. In fact, the manifestation of autism that began with the vanishing of skills of a child who was developing normally set the stage for how a parent felt robbed of a parenting experience to which they aspired. It offers a deeper insight into several impairment effects of autism; of these, hidden disability stands out and makes autism more complex because the child appears normal. This understanding may help professionals reflect on why parents fear being judged about their parenting capacities. The quality of interaction that the parent has with their child with autism may also be surprising for practising professionals who may not fully appreciate the intricacies of interacting with a child with autism. It is also important to realise at a parent level how autism rules family dynamics by fragmenting family time, and how parents experience guilt for neglecting their other children and not providing them with a normal parenting experience. Finally, this thesis reinforces the expectation for parents to be experts in the field of autism because they engage with a professional world

that on one hand is not able to instil confidence in them concerning the effective management of autism, and on the other hand expects parents to constantly articulate and pre-empt the needs of the child.

At an individual level, this thesis offers insight into the various domains of the parents' QOL that are restricted. They experience a loss of control over their life because of a compulsive need to prioritise their child with autism. The irony is that there is no sense of pleasure attached to caring for a child with autism. Parents also experience an encroachment in their physical and mental space, leaving them tired and exhausted. Autism affects their ability to make progressive choices in their social life and vocation. Finally, their sense of self is blurred or narrowed: their role in life primarily revolves around the care needs of the child with autism; and their capacity to perform effectively in other roles as a wife/husband, daughter/son, friend or earning family member is significantly affected.

11.9.2 Implications for Practice

It is important to consider the implications of this thesis for three dimensions of practice: direct practice, management practice and policy practice.

Many of the implications for educational practice transfer to direct practice. The grounded theory developed in this thesis gives social workers yet another tool in their kit to assess the needs of children with autism and their families. Each of the three categories of the theory 'Oppression' may assist social workers to broaden their insight into the nuances of autism. It can be argued that this theory provides a real-time snapshot of living with a child with autism. It also tells the story of the parent capturing the indentations of how they want to express their experience. The first category 'new normal' may assist social workers in undertaking a comprehensive needs assessment of the child and understanding the impairment effects of autism on the child and the family. It also prompts social workers to be prepared and equip themselves with alternative communication aids like PECS or SIGN when engaging with a child with autism. The second category 'ongoing

burden' may be helpful in completion of the carer's assessment with parent(s). It provides indicators of the various areas in parents' lives that have been affected by caring for their child with autism. This may help social workers predict the sustainability of parents in the caring role and use this valuable information for transition and long-term planning. The third category 'limited help' might be particularly useful for reflective practice as it calls for social workers to pause and make a critical evaluation of their current practice and its effects on parents. It provides indicators for how to approach their practice in a way that will prove more effective to their clients/target group.

From the perspective of management practice, this thesis calls for a strong commitment to the training of social workers by improving their knowledge base and skills to make them competent in the field of autism. As autism is a spectrum condition, it is necessary for professionals to understand the differences among the variants on the spectrum to target their interventions more effectively. The findings of this research also call for a review of current service standards within local authorities that stipulate time frames for assessment and response. Parents need a response from social workers that is timely and they would benefit from more proactive engagement from social workers, in contrast to the existing situation in which the onus is on parents to follow up with social work.

This research also revealed that the study local authorities did not appear to maintain databases that identify the autism cases they deal with each year, their variants and so on. The study local authorities are reliant on health board data in relation to autism numbers in their region. However, it cannot be assumed that all clients identified in the health board database use local authority social work services, and vice versa. A more targeted scoping exercise specific to the study local authorities would be beneficial to better document the autism variants in the area and incorporate such data into the planning and improvisation of services.

This research also calls for improved coordination of services, particularly between health and social work. Parents suggested that it might be more beneficial if a referral to social work were initiated by the health professional at the point of diagnosis. At the time of the study, it appeared that parents are bombarded with information leaflets post-diagnosis and expected to make contact for help while battling to come to terms with their child's diagnosis. Parents believe that a follow-on referral pathway to social work would be more effective and would enable them to have one point of contact for accessing information and assistance for help. This also implies that in principle the menu for help should be offered to parents proactively by social work, and the social work assessment process can begin early in an attempt to avoid a state of desperation for parents.

Moving on to policy practice, this research reinforces the dominance of caregiving in the parents' lives, with parents anticipating that they will be the carers of the child post-childhood, even into adulthood. This highlights the prolonged and sustained caring that a parent does on a regular basis. It is important for policy makers to consider the physical and mental health implications for the parent of prolonged caring and the potential effect of this on health and social care services. It was also established in the study that parents, especially female parents, often had to give up their career aspirations, which suggests that parents are not utilising the training and expertise they have had in their field. Policy makers might examine adequate and creative employment support to promote engagement in meaningful, income-generating enterprises that will boost the morale of parents and optimise their opportunity to be a contributing member of society.

11.9.3 Implications for Research

The following are some future research prospects identified on the basis of the findings of this thesis:

research exploring parents' experiences of living with adolescents with autism, which could shed light on the projected long-term care needs of this client group

research into the early manifestations of autism pre-diagnosis might be helpful in exploring whether autism does trigger a loss of acquired skills

research into the circle of informal support for the child with autism and their families will facilitate understanding of the challenges and barriers in extending help

an observational study into the parent–child interaction would be useful to corroborate the findings of the parent–child interaction elements identified in this study

from a service perspective, further research is required to understand specifics of interventions offered by specialist autism providers and how this input differs from that of conventional providers of disability

research exploring the plausibility of new and flexible models of respite for children with autism would be beneficial for service planning and delivery

research on SDS and personalisation and its role in offering flexible service delivery to children with autism and their parents may be of interest.

Chapter 12: Conclusion

12.1 Introduction

'Conclusions seek to tie ends together, to wrap up, to make tidy' (Hall, 2005, p. 275). The purpose of a conclusion chapter is to reflect on the research process. This involves three aspects in the present case. First, I acknowledge the limitations of the research and explain it in the broader context. Second, I evaluate the substantive theory developed in this study using the grounded theory research process. As portended in the research methodology chapter 5, I evaluate the research against the four criteria developed by Charmaz (2006) for grounded theory research evaluation: criteria of credibility, originality, resonance and usefulness. Third, I will document some personal reflections on the research journey.

12.2 Limitations of the Study

It is recognised that using qualitative methods in research poses problems regarding the extent to which findings may be generalised. This is because of the small number of respondents involved compared with the magnitude of sample necessary in quantitative studies. Therefore, it is acknowledged that a potential weakness of this relatively small-scale qualitative study relates to making claims of generalisability. This is a challenge of this thesis because the research was limited to three study local authorities in Scotland. These were purposively selected, which could be open to the criticism of not being representative of the world of parents beyond these study authorities in Scotland.

The issue of generalisability is approached in this section from two perspectives: by examining how it was addressed within the research; and by exploring the broader issue of generalisability within qualitative research. This was addressed within the research in part by the sampling strategy. The study recruited 13 female parents, 10 male parents, 12 social workers and 3 operational managers across three study local authorities. Of the 23 parent

participants, 19 were in a couple relationship, 3 were single parents and 1 parent had re-partnered (reconstituted family). The sample also had representation from ethnic minorities including Asian, African, Middle Eastern and European backgrounds. The parent participants' age range was wide. The social workers recruited from each of the study local authorities had diverse characteristics, including tenure of employment, specific roles with disability teams (specialist worker for autism, senior social worker) and so on. In addition to ensuring diversity among participants, the chosen three study local authorities ensured diversity in this aspect also: according to health board statistics, two of the study local authorities had the highest number of children and young people with an ASC; and the third was known for its exemplary and award-winning service delivery to the community. Thus, there was variability among the participants recruited. There was no indication that the study local authorities in which this research was conducted were different in any respects from other Scottish authorities as the policy and legislative context that underpinned all the Scottish local authorities was the same.

One of the main limitations of the study was the difficulties in undertaking dyadic recruitment of social workers and parent respondents. The data gathered would be richer in context if this study had been able to recruit social workers already working with the parent participants, allowing the researcher to make a dyadic connection.

There was no indication that the study local authorities in which the research was conducted were atypical. While there may be subtle differences in the organisation and structure of social work teams catering to disability, the grounded theory that emerged in this thesis has identified that the QOL experiences of parents is unlikely to differ markedly for parents living in other local authorities in Scotland. Indeed, the comparative research that has been undertaken emphasises significant commonalities across the four jurisdictions of the UK (Stafford et al., 2012).

More important is the much broader discussion about the issue of generalisability in qualitative research. Silverman (2011) offers a useful discussion of differences within qualitative research between those who see qualitative research as being purely descriptive, in which case generalisability is not an issue, and those for whom it is a concern. He follows Bryman (1988) in arguing that qualitative research should aim to generalise to theoretical propositions rather than to populations. This is entirely consistent with the grounded theory approach used here.

As with all research, there are limitations; in this instance the researcher is part of the study and no researcher is completely objective (Charmaz, 2006). Constant comparative analysis of the data was utilised along with self-awareness, journaling and discussions with supervisors to minimise any effects of methodological limitations of the study.

12.3 Evaluating the Thesis

As discussed in the methodology chapter (chapter 5), Charmaz (2006) identifies four criteria for constructivist grounded theory studies: credibility, originality, resonance and usefulness. These provide a useful lens through which to retrospectively analyse the findings of this thesis. Charmaz poses a series of questions for the researcher to answer when addressing the criteria; these provide a useful framework for this section of the chapter.

12.3.1 Credibility

In terms of credibility, I argue that intimate familiarity has been achieved with the topic under exploration; the challenge was achieving sufficient distance between the researcher and the area under discussion. Familiarity was achieved through immersion in the data. From within the target population, a wide range of participants as identified in terms of gender, ethnicity, age and residence across three study local authorities. A notable achievement of this study was the participation of almost equal numbers of male and female parents. A review of the literature targeting parents of children with

disabilities revealed a frequent over-representation of mothers and an under-representation of fathers. I also argue that the use of theoretical sampling increased that range. In addition to interviewing parent participants, social workers and operational managers were also interviewed to offer comparative perspectives of the topics being explored.

Further, findings are presented in sufficient detail to support the conclusions that have been reached. This thesis provides links between the data that were gathered and the final theory that was developed. The links between the data and the theory are demonstrated by the provision of excerpts from the interviews and the development of the categories; these categories provide an insight into the data that informed the development of each category. These excerpts and the associated discussion are provided to allow the reader the opportunity to develop an independent assessment of the study.

In short, it is asserted that this thesis offers a considerable level of credibility.

12.3.2 Originality

The approach to this study was radical and to an extent controversial because it set out to understand the QOL experiences of parents without utilising the standard QOL measurement tools. However, this approach adds to the originality component of this thesis. It is contended that there are two main indicators of originality. The first is the application of GTM. While grounded theory is not new—indeed, it is among the most popular qualitative methods (Oktay, 2012) with an extremely good fit with social work (Gilgun, 1994)—it is not widely used in social work research in the UK. The second is the emergence of the core category of ‘new normal’. It is suggested that the findings offer a different perspective on the QOL experiences of parents of children with autism and an additional lens through which to examine QOL. The analysis of the data has provided a conceptual rendering of the QOL experiences of parents living with a child with autism and explains the realities associated with the development of a new normal. This is completely

different to the concept of normalcy parents had about parenting their child. This is an original approach to studying the QOL experiences of parents of children with autism as most studies primarily focus on the experiences of parents on the autistic spectrum. These may include all variants of the condition (e.g., autism and Asperger syndrome).

This study also focused on recruiting an almost equal number of male and female parent participants, which adds to its originality. Originality is further enhanced as limited studies investigate the QOL experiences of parents without utilising standard measurement tools. This study was the first of its kind according to feedback received while negotiating access with the study local authorities.

While a number of aspects of the findings are familiar in the literature—for example, domains of QOL encapsulated in the subcategory ‘ongoing burden’—I argue that there are two key aspects that make the perspective offered here original. The first aspect is the holistic nature of the theory presented, in particular the finding that one of the subcategories emerged as the core category to give a plausible description of the parents’ QOL experiences and that each of the categories qualified various aspects of their QOL. Second, this thesis explores the parents’ perspectives and retains a sustained focus on the concerns of participants throughout the thesis.

12.3.3 Resonance

The third of Charmaz’s criteria for the evaluation of grounded theory is that of resonance. She poses the question of whether the theory makes sense to participants or people who share their experiences. As parents who participated did not consent for me to contact them to discuss the initial findings, member checking was not possible. However, earlier iterations of the theory were shared with a number of people including parents with whom I worked while practising as a social worker. I also shared the findings with my social work colleagues and managers. I engaged in discussions in web forums on dedicated social networking sites for parents of children with

autistic spectrum conditions. As far as can be ascertained, the theory as developed here was received positively with a number of participants subsequently initiating correspondence or dialogue on web forums. These discussions have allowed the drawing of links between the experience of participants and the wider community of interest. Although they were based on early iterations of the thesis, the final version was both informed and strengthened by those discussions, which emphasises that the theory has resonance or 'grab'.

12.3.4 Usefulness

The final criterion is that of usefulness, which Charmaz divides into questions about whether interpretations are offered that people can use; whether there are implications for wider generic processes; and whether there are implications for further research in other substantive areas. Implications for education, practice and research were discussed in the previous chapter. While not wishing to overstate the importance of this thesis, I argue that the application of the developed theory has the potential to contribute to improved practices in social work with a view to improving the QOL experiences of parents of children with autism and their families. Hence, it has the potential to improve outcomes for children with autism and their families as outlined in the *Scottish Strategy for Autism* (2011) and in so doing answer Charmaz's (2006, p. 183) last question about usefulness: 'How does it contribute to making a better world?'

In short, I argue that this thesis meets the criteria of credibility, originality, resonance and usefulness and as such makes a unique contribution to knowledge about parents of children with autism.

12.4 Personal Reflections

Completing this research has been one of the most dynamic and challenging processes that I have ever undertaken in my academic life. Writing this section produces a certain level of exhilaration and contentment that I cannot

describe in words. While being awarded a PhD would be a perfect ending to my research journey, I hope that the information I have provided will contribute to better outcomes for the parents of children with autism. The decision to engage in the process of undertaking a PhD was relatively simple given my interest in academia and a deep desire to understand a client group about whom I have been passionate since the initial days of my social work training in India. Committing to completing a PhD has been a test in itself. If not for the unconditional support of my family and the immense patience and expert guidance of my supervisors, I do not think I would have the strength and resilience to complete this mammoth project. Long, hard years of engaging in a research project opens up many questions. How has it affected me as a person? What interested me the most in the research process? What are some of the takeaway learnings?

For me as a person, the process has been one of the loneliest and most isolating processes I have ever experienced. It was also a phase in my life when my personal circumstances underwent several transitions. I began my PhD when I was living in Greenock, Scotland and I am wrapping it up in the beautiful city of Melbourne, Australia. Becoming a mother of two was life-changing during my PhD years and my daughters became another pillar of strength and motivation. A hard blow to come to terms with was the loss of one of my supervisors, who played a major role in shaping my research and developing my skills as a researcher. Being a part-time and long-distance student, I did not have the opportunity to take full advantage of the learning environment that the university offered. I therefore missed out on the discussions and group learning which I would have loved to be a part during my PhD years. However, what I did realise is that I have an undying spirit to learn and constantly improve. I have a quiet determination that pushed me through the numerous challenges that came my way.

Having completed all my education in India, doing a PhD at the University of Edinburgh was a complete change in scene for me on both an academic and personal front. I went through a process of deconstructing some of the

learning I did in India and reconceptualising it in a format that is more appealing to the research journey that I had embarked on. Language was another area where I had some concerns. However, living and working in Scotland acclimatised me to the language and culture and helped me shed my initial reservations. The process of completing a PhD has made me a more resilient and mature human being. On the academic front, this process has constructively challenged me to develop insights into the nuances of research and to hopefully make useful contributions to the existing knowledge pool.

Like any other PhD student, I was clear about my aim and my method and breaking this barrier was not easy, especially for someone like me who is a known control freak. Each stage of my PhD had huge learning curves, from the proposal development stage through to thesis writing. It is no surprise that interviewing the participants and negotiating access were the two aspects of the PhD process that I enjoyed the most. I felt most comfortable and natural during this phase and I cannot deny the parallels it had with the day-to-day job of a social worker. I felt humbled and privileged to be part of the story-telling process of the parents as they recollected some of the most painful moments of living with their child with autism.

Data collection was an extremely painstaking and time-consuming experience. I travelled extensively and during odd hours, particularly to catch up with the male parents whose most convenient time to talk was in the evenings. One particular incident that stays with me is the frustration of making three separate trips to Edinburgh and back to interview a male parent and still not being successful in speaking to him. Being a single parent, he obviously had to prioritise the needs of his children and needed to cancel the appointment with me all three times.

The experience of talking to social workers and operational managers was quite different from that of speaking to parents. I enjoyed a sense of camaraderie with the social workers who thought that being one of them, I would better understand their perspectives.

This brings us to the issue of me being an insider. This research process challenged me to stand back and not allow myself to get too pulled into the world of the participants. During the final writing of this thesis, I had resigned from my job as a social worker in Scotland and had relocated to Australia. This had in a sense broken the link I had with the world of the parents and social workers and helped me to view the data more as a researcher.

The production of this thesis has been another major challenge for me given that I am a relatively new entrant to the academic world; the academic writing style did not come naturally to me. I also had difficulties in switching from the writing style of a professional social worker to that of an academic researcher. I often went through phases of writing fatigue that were excruciatingly frustrating. Deconstructing the grounded theory analysis process was another challenge because grounded theory is not a commonly used analysis approach in social work research and the guidance available in the literature varied quite significantly. Hence, grappling with the concepts and analytical framework of the grounded theory research process was another hurdle that I believe I jumped reasonably well.

Overall, I believe these seven years of my PhD journey will always be cherished as a phase in my life that has brought out the best in me as a professional and as an academic.

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Policy Documents

GIRFEC (Getting It Right for Every Child)

Scottish Strategy for Autism 2011

Caring Together: The Carers Strategy for Scotland 2010-2015

Self-Directed Support (SDS)

Commission on the Future of Public Services (Christie Commission)

Commissioning Social Care, Audit Scotland

Appendix i - Informed Consent form for parents

Anonymity and confidentiality

Research Participant (Parent) Informed consent and Confidentiality Statement

INFORMED CONSENT FORM FOR PARENTS TO PARTICIPATE IN RESEARCH STUDY

Study Title :	An Exploration into the quality of life experiences of parent carers of children with autism in Scotland
Researcher :	Deepa Kuriachan, PhD Student
Department& University :	School of Social and Political Science, University of Edinburgh

What is it? I am doing a research study that aims to explore the quality of life experiences of parent carers who have a child with autism and who may/may not be receiving services from social work for their child. This research study is carried out under the supervision of Mrs. Susan Hunter and Ms. Janice McGhee, Senior Lecturers in Social Work, School of Social and Political Science, University of Edinburgh.

How will this be done? I will be speaking to the father and/or mother who undertake parental care responsibilities of a child with autism; as well as to

social workers and operational managers. I would like to speak to you and learn about your experiences of having a child with autism.

Will you tell anyone what I tell you? No I will not, all information will be treated as confidential. The only exception to this will be when there is evidence that a child is at risk of harm/neglect; in which case I have a duty to speak to the appropriate agency.

How will this information be used? This information will be processed to write up my research thesis and produce a summary of the key findings which may inform the current service delivery. It will also be used to write journal articles in the future. I will not use real names or any details so that no one can recognize you. A summary of the key findings will be made available for you at the end of the research process.

Will it affect the services I receive from social work, if any? No, participating in this research study will not affect any services that you may be currently receiving from social work.

I am interested to take part! What should I do? I really appreciate your interest to take part in this study. Please complete a simple form attached along, sign and date it, and return it in the stamped envelope enclosed. Once I receive the form, I will get in touch with you shortly to get an appointment to speak to you.

Please don't hesitate to contact me if you have any questions to ask in relation to this study. My contact details are:

Deepa Kuriachan, School of Social and Political Science, University of
Edinburgh, Chrystal Macmillan Bulding, 15a George square, Edinburgh, EH8
9LD. Ph:07702786723; Email: D.Kuriachan-1@sms.ed.ac.uk

Please detach and retain this sheet for future reference

CONSENT FORM

An Exploration into the quality of life experiences of parent carers of children with autism in Scotland

Please tick the boxes if you agree

I am interested to take part in this research study ☐

I consent the researcher to audio record ☐

what I have to say

I understand that I can end the interview/recording ☐

whenever I want

I understand that I do not have to answer all ☐

questions asked

I understand that researcher will have to contact ☐

appropriate agency if there is evidence that a

child is at risk of harm/neglect

I understand that my views and comments may be ☐

used in reports/journal articles but my identity

will not be compromised

Participant's name.....

Participant Signature..... Date.....

Please detach this form after completion and return it in the stamped envelope enclosed.

Appendix ii - Informed consent form for social workers and operational managers

Anonymity and confidentiality

Research Participant (Social Workers and Operational Managers) Informed consent and Confidentiality Statement

INFORMED CONSENT FORM FOR SOCIAL WORKERS/OPERATIONAL MANAGER TO PARTICIPATE IN RESEARCH STUDY

Study Title :	An Exploration into the quality of life experiences of parent carers of children with autism in Scotland
Researcher :	Deepa Kuriachan, PhD Student
Department & University :	Department of Social Work, School of Social and Political Science, University of Edinburgh

Aim The aim of the research is explore the quality of life experiences of parent carers who has a child with autism and who may/may not be receiving services from social work for their child. This research study is carried out under the supervision of Mrs. Susan Hunter and Ms. Janice McGhee, Senior Lecturers in Social Work, School of Social and Political Science, University of Edinburgh.

Methodology I will be speaking to the father and/or mother who undertake parental care responsibilities of a child with autism; as well as to social workers and operational managers.

Findings This information will be processed to write up my research thesis and produce a summary of the key findings which may inform the current service delivery. It will also be used to write journal articles in the future.

Confidentiality Information gathered in this research study will be kept confidential. It will be stored in a secure place and destroyed within a year of completion of the PhD programme. Participant's name and identifying details will be changed to protect the identity of participants in any reports or journal articles.

Participation I would like to speak to you to gain a better understanding of the services available from social work for a child with autism and their family. I am also interested to know your views and opinions related to the same.

Interested to take part? Please complete the attached consent form and return in the stamped envelope provided. I will be in touch shortly for an appointment.

Please don't hesitate to contact me if you have any questions to ask in relation to this study. My contact details are:

Deepa Kuriachan, School of Social and Political Science, University of Edinburgh, Chrystal Macmillan Building, 15a George square, Edinburgh, EH8 9LD.

Ph: 07702786723; Email: D.Kuriachan-1@sms.ed.ac.uk

Please detach and retain this sheet for future reference

CONSENT FORM

An Exploration into the quality of life experiences of parent carers of children with autism in Scotland

Please tick the boxes if you agree

I am interested to take part in this research study ☐

I consent the researcher to audio record what I
have to say ☐

I understand that I can end the interview/recording
whenever I want ☐

I understand that I do not have to answer all
questions asked ☐

I understand that my views and comments may be
used in reports/journal articles but my identity
will not be compromised ☐

Participant's name.....

Participant Signature..... Date.....

Please detach this form after completion and return it in the stamped
envelope enclosed.

Appendix iii - Topic guide for focus group

Size : 4-6 (max:6)

No. of Focus Groups : at least 1, maximum 2

Duration : 1 hour (approx)

Selection : Father or mother of a child with autism

Step 1: Introduction

I'm very grateful to you all for sparing time to participate in this focus group. The purpose of this focus group is to establish a base of evidence around two main questions

(1) What does the term quality of life mean to you?

(2) What are your views of the services available from the LA for children with autism and their families and how does it impact on your quality of life experience?

There are no right or wrong opinions, I would like you to feel comfortable saying what you really think and how you really feel.

I hope to tape record the discussion. I may also take notes to ensure accuracy of data collected.

May I assure you that all of your comments will be kept in strict confidence and that the report of the research will reflect collective response and will not list names of those who participated in this focus group. The participants have the right to withdraw at any time.

We will try to have this discussion in two sessions with a break in between.

Consent form to be signed and collected before the start of the discussion

Step 2: Ice breaking Session

Ask participants to introduce themselves:

Their name

Which area do they come from

Favourite food

Step 3: Suggested Ground Rules

A small discussion to obtain consensus on ground rules (e.g. mobiles in silent mode)

anonymity

confidentiality

taking turns to talk

Step 4: Key Question 1 (20 - 30 minutes)

Q1.1 What are the important things that contribute to your quality of life?
(Prompt: Literature concerned discuss about the following domains viz. viz. Emotional, Psychological, vocational, financial, marital, support network)

Q 1.2 What interferes with your quality of life? (Prompt: experience of parenting for their son or daughter with Autism, experience of obtaining a diagnosis, attitudes of extended family, community)

Q1.3 Does these remain constant or change with circumstances?

Break (20minutes)

Step 5: Key Question 2 (20 - 30 minutes)

Q2.1 What are your views of the services available from the LA for children with autism and their families (Prompt: what services are known to be available, how do you feel about accessing these services, carers assessment, SDS,

Q2.2 how does it impact on your quality of life experience? (Prompt: positive, negative or no change)

Q2.3 What would be an ideal service for you?

Step 5: Closing Session

Summarise the main themes arising from the discussion. Offer them the opportunity to see the summary. Ask the group if there was anything more they wanted to add. Thank the group for their participation. Debrief.

Appendix iv - Semi structured interview schedule for parents

Schedule for Qualitative Interviews

The initial schedule (See below) was developed from the themes that emerged in focus groups and the schedule continued to evolve as the interviews progressed with the parent participants; it became more structured.

Themes	DOMAINS/TOPICS	QUESTION FRAMES Suggested form of questions
Quality of Life experience	These questions deal with how parent carers describe their quality of life experience and the main domains determining their experience.	What are the most important things in your life? What does the term quality of life mean to you?
Parenting a child	This set of questions are designed to discover Challenges/specific difficulties of parenting Care giving strain Eco-cultural	How is your experience of being a parent? I am keen to hear more about your positive experience of parenting?

	adaptations e.g. change in routines	
Experience of Parenting a child with Autism		<p>Could you describe your experience of parenting a child with autism?</p> <p>Have there been any challenges? If so, could you tell me more about it?</p>
<p>Quality of Life domains</p> <p>Diagnosis, Emotional, Psychological, vocational, financial, marital, support network</p>	<p>These questions are designed to explore further</p> <p>The Indicators described by parent carers</p> <p>Domains suggested in literature</p>	<p>When did your child get his diagnosis?</p> <p>What did you think when he/she was given the diagnosis?</p> <p>Experience about diagnosis</p>

Emotional/psychological Domain	These questions cover the emotional experiences of parent carers	How would you describe your emotional state at this point of time? Mental health What about the attitude/support from your community?
Support Network		
Financial Domain	These questions are designed to describe relation between economic factors in the context of caring for a child with autism	Did the care giving responsibilities/needs have an impact on your finances? If so how?
Vocational Domain	As above but explore the impact on careers	Do you have paid employment? How do you balance work

		and life?
Family/Marital Domain	These questions are designed to investigate the challenges in care giving and its impact on relationships (harmony/discord)	<p>Tell me a bit more about your family life?</p> <p>Has having a child with autism in anyway influenced (positively or negatively) the relationship with your partner/husband/wife?</p> <p>How would you describe your feelings about your marital relationship?</p>
Services from Local Authority	These questions are designed to map the existing services provided for parent carers by local authority; are there adequate and appropriate services and the experiences	<p>Do you receive any services from your local authority?</p> <p>What are they? (use prompt list)</p> <p>Did you have any difficulties</p>

	of parent carers	<p>in getting a service?</p> <p>Challenges?</p> <p>What is an ideal service according to you?</p>
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Appendix v-Semi structured interview schedule for social workers/operational managers

Themes emerged from pilot interviews and began to further develop as the interviews progressed

Domains	Questions
Introductory	<p>Which team do you work in?</p> <p>Experience</p> <p>Target group</p> <p>Source of referrals</p> <p>Expectations of families when they approach social work</p> <p>Challenges if any</p>
Eligibility/Criteria for Service	<p>Eligibility criteria for the service</p> <p>Services offered</p> <p>Process of assessment</p> <p>Carers Assessment</p>

Service provided	<p>What are the services available to be offered to your client group?</p> <p>Elaborate on any autism specific services</p> <p>Carers assessment and what it means for the family</p> <p>DP/SDS</p>
uptake of Service	<p>In your view, is there an increasing demand for services from children with autism and their families?</p> <p>Can you think of any barriers to people accessing your service? E.g. stigma</p> <p>What is your view on the uptake of service by ethnic minority communities in your council?</p> <p>Are there any specific barriers i.e. language, lack of availability of information etc?</p>

Multi agency working	<p>What other agencies do you work with?</p> <p>Could you describe your experience on multi agency working?</p> <p>Any challenges?</p> <p>What needs to change/develop (if any) with regard to multi-agency working in your view?</p>
Parent Carers	<p>In your view, how does the services offered impact on the quality of life experiences of the parent carers of children with autism?</p>
	<p>In your view, are there any gaps in the service or scope for improvement?</p> <p>Could you describe an ideal service for children with autism and their parent carers?</p>

	<p>Do you anticipate any service development in the future in the light of Autism strategy rolled out by Scottish parliament in November 2011?</p>
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Appendix vii - Basic profile of parents

BASIC PROFILE (Parent)

1. Initial Details

1-1. Interviewer

1-2. Interviewee's name

1-3. Interviewee's address

1-4. Age of the child

1-5. Sex of the Child

1-6. Meeting place for interview

1-7. Date/month/year:

1-8. Consent Form completed: Yes/ No (Please circle your answer)

2. Sex of the respondent: Male/Female (Please circle your answer)

3. Ethnic Origin (Please tick one of the below)

White	British
	Irish
	Scottish
	Any other white background
Mixed	White and Black Caribbean
	White and Black African
	White and Asian
	Any other mixed background
Asian or Asian British	Indian
	Pakistani
	Bangladeshi
	Any other Asian background
Black or Black British	Caribbean
	African
	Any other Black background *
Chinese	Chinese
Other ethnic group (OE)	Please state:

4. Age of the respondent (Please circle your answer)

16 – 19

40 – 49

20 – 29

50 – 59

30 – 39

60 – 64

5. Type of Accommodation (Please circle your answer)

(a) Rented/Owner Occupied

(b) Bedsit/Flat/Maisonette/Terraced/semi-detached/detached

6. Are you in paid employment Yes/No (Please circle your answer)

If Yes, Full time/Part time

7. How many children do you have?

8. Family Structure, (Please circle your answer)

(a) Single

(b) Couple

(c) Reconstituted family

Appendix viii - Basic profile of social workers and operational managers

BASIC PROFILE (Social Workers/Operational Managers)

1. Initial Details

1-1. Interviewer

1-2. Interviewee's name

1-3. Interviewee's address

1-4. Meeting place for interview

1-5. Date/month/year:

1-6. Consent Form completed: Yes/ No (Please circle your answer)

2. Sex of the respondent: Male/Female (Please circle your answer)

3. Ethnic Origin (Please tick one of the below)

White	British
	Irish
	Scottish
	Any other white background
Mixed	White and Black Caribbean
	White and Black African
	White and Asian
	Any other mixed background
Asian or Asian British	Indian
	Pakistani
	Bangladeshi
	Any other Asian background
Black or Black British	Caribbean
	African
	Any other Black background *
Chinese	Chinese
Other ethnic group (OE)	Please state:

4. Age of the respondent (Please circle your answer)

16 – 19

40 – 49

20 – 29

50 – 59

30 – 39

60 – 64

5. Team that you work in

6. Form of Employment Fulltime/Part time (Please circle your answer)

7. How many cases do you handle?